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Plenary Session
Day 1

Tuesday, January 11, 2000

Perinatal HIV Transmission Grantee Meeting

Atlanta Marriott North Central
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January 11–12, 2000

Tuesday, January 11
Moderator— Janet Cleveland, Centers for Disease Control and Prevention (CDC)

Janet Cleveland opened the meeting on January 11 at 9:00 A.M. by introducing David Holtgrave, Director of the Division of HIV/AIDS Prevention, Intervention Research and Support of CDC's National Center for HIV, STD, and TB Prevention; and Julie Scofield, Executive Director of the National Alliance of State and Territorial AIDS Directors (NASTAD), who welcomed all attendees as follows.

Welcome and Opening Remarks

David Holtgrave, Centers for Disease Control and Prevention (CDC)

Good morning and welcome!

As you know, last year $9.1 million was appropriated for perinatal HIV elimination activities. It was divided among three different kinds of activities.

- $6,300,000 to 16 state and local health departments
- $1,866,667 to 26 state and local health departments working on enhanced perinatal surveillance
- $933,000 to 5 national organizations

Together, that group of partners along with CDC makes a strong coalition for perinatal HIV prevention. CDC is committed to perinatal HIV elimination. The terms "control," "elimination," and "eradication" have received attention recently. In a book by Walt Dowdle and Don Hopkins, *The Eradication of Infectious Disease* lists seven criteria for eradication of infectious diseases:

- Scientific feasibility—Eradication is possible when
  - there is epidemiologic vulnerability of the disease; i.e., an Achilles heel;
  - there are practical interventions available; and
  - there has been demonstrated feasibility of elimination or control in certain geographic areas.
- Political will and popular support—Eradication is possible when
  - the public perceives a burden of the disease;
  - there is an expected cost of eradication;
  - there is a synergy of elimination efforts with other interventions; and
  - there is a necessity for true elimination (to zero) rather than control at some acceptable level.

Although with perinatal HIV we are concerned more with control and elimination than eradication, all or many of these criteria have already been met. This drives our enthusiasm toward today's partnerships with the state and local health departments, which will work on the programmatic and surveillance efforts and with the national organizations. Together we can take the next step toward meeting all the above criteria necessary for eliminating perinatal HIV transmission. Thank you.

Julie Scofield, National Alliance of State and Territorial AIDS Directors (NASTAD)

Good morning, everyone. NASTAD represents the nation's chief state health agency AIDS program directors, who have responsibility for administering HIV/AIDS health care, prevention, education, and supportive service programs funded by both state and federal governments. NASTAD is funded by CDC to provide peer-based technical assistance to health departments and community planning groups for planning and prevention programs.

I was asked to speak a little bit on why we are here and how we got here and to provide a brief legislative history of the perinatal HIV prevention program.

In fiscal year 1999 (FY 99), Congress appropriated $10 million for CDC to implement Section 2625 of the Ryan White CARE Act (RWCA) Amendments of 1996. Section 2625 was a provision of the law, when the RWCA was last authorized, that was championed by Representative Tom Coburn of Oklahoma. After negotiations, this provision of the law authorizes grants to states for activities to reduce perinatal transmission of HIV, including

- Making available to pregnant women appropriate counseling on HIV disease
- Making available outreach efforts to pregnant women at high risk for HIV who are not currently receiving prenatal care
- Making available to such women voluntary HIV testing for such disease
- Offsetting other state costs associated with the implementation of this Section and Subsections (a) and (b) of Section 2626, of which
    - Subsection (a) relates to determining the rate of reported AIDS cases due to perinatal transmission
    - Subsection (b) relates to determining causes of perinatal transmission
- Offsetting state costs associated with the implementation of mandatory newborn testing in accordance with this Title or at an earlier date than is required by this Title

Report language accompanying the FY 99 funding bill placed emphasis on state-administered activities including outreach, counseling, and voluntary testing of pregnant women, rather than mandatory testing of newborns. Priority was given to states that have the greatest proportion of HIV seroprevalence among childbearing women, as determined by the most recent data available from CDC.

The perspectives and challenges of the states are as follows:

- CDC implementation and process for making the awards was extremely lengthy, nearly a year, and was not well communicated to eligible state and local grantees.

- Activities and expectations (for expenditure of these awards) must relate to award amounts. The award amounts range significantly, from $50,000 to $1 million.
- State and local health departments play a pivotal role in planning, coordinating, and implementing perinatal prevention activities.
    - The health department AIDS programs administer the RWCA.
    - The states administer Title II, including the AIDS Drug Assistance Program (ADAP).
    - The cities administer Title I.
    - States coordinate all CARE Act grantees in their jurisdictions.
        - Health departments are also funded through CDC's HIV Prevention, Surveillance/Epidemiology, and Sexually Transmitted Disease (STD) programs.
        - State resources are being used.
        - State agencies also have relationships with Medicaid, substance abuse, and Maternal Child Health (MCH) programs.
- The biggest challenge is bringing the hardest-to-reach pregnant women into prenatal care.
- Another challenge is providing accessible, culturally appropriate HIV prevention and care services to women of childbearing age.
- We have an opportunity this year, because of the Congressional Black Caucus Initiative (CBC) and new directly funded community-based organizations (CBOs) to make this initiative go even further than it might on its own by linking with the new CBOs that are targeting their HIV prevention efforts to some of our most vulnerable communities.

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General Meeting Information—Martha Rogers welcomed participants and gave an overview of the meeting format. Project officers and other contact persons were introduced, and all are listed in the Participants List. Mary Helen Witten also welcomed participants and discussed meeting logistics.

Plenary Sessions—Janet Cleveland, Associate Director for Community Planning and Capacity Building, DHAP-IRS, CDC, moderated this session. After extending a warm welcome to everyone present, she introduced the first speaker.

The CDC Vision of Prevention of Perinatal HIV Transmission— Martha Rogers, CDC

The vision of what CDC hopes to accomplish with these projects is one that should be molded and shaped to fit the collective vision of all participants. HIV and AIDS in children became a leading cause of death in young children under 5 years of age; the number of perinatally acquired cases peaked in 1992 when there was little that could be done for these women and children. Then in 1994, the Perinatal AIDS Clinical Trials Group (PACTG) 076 found that by giving zidovudine (AZT) to the mother during pregnancy and to the newborn, we could dramatically reduce by two-thirds the mother's likelihood of transmitting HIV to her baby. Subsequently, the number of perinatally infected children plummeted. A number of items are credited for contributing to this decline.

- National guidelines were developed and published quickly and disseminated widely by CDC, Health Resources and Services Administration (HRSA), and others.
- The Food and Drug Administration (FDA) changed the labeling of AZT to reflect the indication for prevention of perinatal HIV transmission.
- The Health Care Financing Administration (HCFA) made funding for treatment available through Medicaid and other programs.
- States passed a number of laws and regulations that helped promote the guidelines.
- Professional organizations developed best practices and encouraged their use among clinicians.
- Private foundations were supportive and provided resources.
- Congress passed legislation designed to evaluate the efforts through both the Secretary's Determination and the Institute of Medicine (IOM) report published in 1998. Later, in 1999, funding was appropriated to help states further reduce perinatal HIV transmission.

As a result of these efforts, the number of pediatric cases of AIDS declined, and AIDS dropped off the list of the top 10 causes of death in young children. These successes led us to explore how we could reduce as much as possible the number of children acquiring HIV infection and even to speculate about elimination of perinatal transmission of HIV. Achieving these goals would require highly effective interventions and implementation strategies. These points of intervention are described in the following steps.

Steps to Prevention Success

1. Pregnant women need to obtain prenatal care.
2. Providers need to recommend HIV testing for all pregnant women.
3. Once testing is recommended, the woman needs to make a decision about testing and must return for results.
4. Women who are infected must be informed of recommendations about prophylactic treatment.
5. These women must be assisted in adhering to the treatment regimen before, during, and after delivery.
6. Women must seek follow-up care for themselves and their babies and must not breast-feed their babies.

Several elements are critical for achieving the goal of prevention of perinatal HIV transmission.

- Linkages, networking, and collaboration among prevention partners must occur. The perinatal prevention program needs to be viewed in the context of the overall HIV prevention program. Maternal Child Health (MCH) programs, hepatitis B programs, and other perinatal prevention programs are potential partners.
- We need successful policies that can be modified as new information becomes available. For example, the U.S. Public Health Service (USPHS) counseling and testing guidelines are currently being revised.
- Outreach efforts must be extended to partners, communities, providers, women, and others.
- Effective and ongoing training must be provided.
- The programs must be monitored and evaluated for effectiveness. The resultant data must be used to modify the programs as needed.
- Continued research will develop better interventions and more effective implementation strategies.

CDC has formed a plan to further reduce perinatal HIV transmission. The plan was designed to work at the national level, but it can be incorporated at the state or local levels as well. The components of CDC's plan include

- **Surveillance—**expanding HIV reporting to all states
- **Research—**performing additional operational research to improve interventions and to learn how to best put them in place and to inform the prevention programs
- **Education and training—**addressing the issue of providers failing to recommend and offer HIV testing to pregnant women
- **Programs—**ensuring the success of programs being carried out by participants of this meeting, the states with the highest burden of disease and national organizations
- **Outreach—**developing partnerships and expanding community efforts
- **Evaluation—**continuously monitoring components of the interventions, their effects at national and local levels, and evaluating local programs as well
- **Policy and legal aspects—**updating prophylaxis and counseling and testing guidelines, encouraging and monitoring state laws and regulations, advocating for and supporting HIV testing of pregnant women as a Health Plan Employer Data and Information Set (HEDIS) measure, promoting model Medicaid-managed care contract language

What are some of the challenges that we're going to face as we try to further reduce perinatal transmission of HIV?

- Increasing prenatal care use, especially among substance-using women
- Making HIV screening the standard of care among all prenatal care providers
- Monitoring the emergence of antiretroviral resistance
- Addressing potential toxicities of antiretroviral drugs, a surveillance activity
- Improving adherence to very complex regimens

We have several themes to keep in mind as we develop these projects over the ensuing months and years.

- **Synergy**—We should maximize what we do in this program to apply not only to our goal, but to preventing HIV in all women, getting women into prenatal care (which helps with other diseases they might have, etc.) by creating synergy.
    - between HIV and MCH programs
    - between HIV and other perinatal interventions (e.g., hepatitis B)
    - between clinical, public health, and community-based programs
- **Collaboration and networking—**You may need to interact with people in health departments and communities that you've not previously had contact with.
- **Communication—**We need to communicate at many levels, such as websites.
- **Flexibility—**Programs need to change to fit with new scientific and evaluation information.
- **Ethics—**We need to adhere to the highest ethical standards and to ensure that our programs respect affected populations.
- **Sustainability—**We do not know how long the funds will continue, but programs need to be developed that will be sustainable beyond this grant.

With those things in mind, I wish us all well over the next couple of days. Thank you.

Update on Enhanced Perinatal Surveillance, Toward Elimination of Perinatal HIV Infection: Surveillance Data to Target and Evaluate HIV Prevention Programs —Mary Lou Lindegren, CDC

The book by Walt Dowdle and Don Hopkins, *The Eradication of Infectious Diseases*, discusses the definition and concept of elimination of an infectious disease:

- **Elimination of perinatal HIV infection.** The definition of "elimination" is reduction to zero of the incidence of infections caused by a specific agent in a defined geographic area, as the result of deliberate efforts; continued measures to prevent reestablishment of transmission are required.
- **Elements of an elimination program.** Dr. Dowdle and colleagues stress the need for an elimination program to "initiate surveillance early and use surveillance information to guide program strategy." Use surveillance as information for action. Surveillance was a key component of smallpox and current polio eradication efforts. The quality and intensity of surveillance increases with the stage of elimination.

Background of Perinatal HIV Transmission Reduction (provides the basis of feasibility for elimination)

1994. Use of maternal and neonatal zidovudine (ZDV) in AIDS Clinical Trials Group (ACTG) 076 reduced transmission from 25% to 8%. The Public Health Service (PHS) recommended ZDV to prevent perinatal HIV transmission.

1995 onward. Data from clinical trials, observational cohorts, and state surveillance systems document perinatal HIV transmission as low as 5% with ZDV.

1994 through 1996. Declining perinatally acquired AIDS in the United States. 15% of HIV-infected women did not receive prenatal care [Surveillance to Evaluate Prevention (STEP) data].

1998. Short-course ZDV regimen in late pregnancy and intrapartum reduced transmission by 50% in Thailand. Observational data in New York State (NYS) suggest a reduction in transmission with abbreviated ZDV regimen begun intrapartum or in the first 48 hours of life.

1997 to present. Increasing use of combination antiretroviral therapy (ART) during pregnancy.

1998. Use of elective cesarean section in presence of ZDV therapy reduced rate of HIV transmission to 1% to 2%.

1999. Combination ART that reduces maternal viral load to undetectable levels may lower risk of transmission to <1%. Nevirapine (NVP), once at labor and delivery and to baby, reduced transmission 47% relative to ZDV.

Description of Perinatal HIV/AIDS Surveillance

Perinatal HIV/AIDS surveillance is the ongoing and systematic collection, analysis, dissemination, and use of population-based information on HIV-infected pregnant mothers, perinatally exposed and HIV-infected children, morbidity (AIDS), and mortality. Surveillance data are collected actively by state and local health departments. The data can highlight successes as well as missed opportunities so that successful strategies can be targeted to areas of need.

Uses of Perinatal HIV Surveillance Data

- Monitor the HIV epidemic in women and children.
- Assess resources needed for prevention, care, and social services.
- Target and evaluate effectiveness of perinatal HIV prevention (receipt of prenatal care, HIV testing, ARV therapy, other interventions to reduce perinatal transmission, HIV status of baby, follow-up care).
- Evaluate implementation of other public health recommendations such as for *Pneumocystis carinii* pneumonia (PCP) prophylaxis, timely HIV diagnosis and treatment.
- Facilitate evaluation of adverse effects of perinatal exposure to ART.

Types of Perinatal HIV Surveillance Data Collected

- Demographic characteristics
- Maternal prenatal care use, testing history, risk, antiretroviral use (ZDV use during pregnancy, week started, labor/delivery), and other antiretroviral use during pregnancy and labor/delivery
- Neonatal ZDV, other antiretroviral therapy, PCP prophylaxis
- Birth history (type of delivery, prematurity, birth weight, birth defects)
- HIV diagnostic and immunologic tests, opportunistic illnesses, mortality

CDC-Perinatal Prevention Plan, Ryan White Care Act 1996

$10 million was appropriated for perinatal HIV elimination activities.

- $6 million to 16 state and local health departments for program activity through the prevention cooperative agreements
- $1.8 to 26 state and local health departments working on enhanced perinatal surveillance
- $1 million to 5 national organizations
- Collaboration needed with HIV prevention, HIV surveillance, MCH, and substance abuse programs

Enhanced Perinatal HIV Surveillance

- Thirty-two states currently have named HIV reporting. Enhanced perinatal surveillance is an expansion of STEP, a surveillance project initially implemented in four states (NJ, SC, MI, LA) in 1996, which was instrumental in the recent Institute of Medicine Report (IOM) findings.
- Enhanced ascertainment of mother-infant pairs: active case finding at pediatric sites and OB hospitals, matching of HIV/AIDS registry to birth registry, laboratory reporting, and women pregnant at the time of report
- Systematic ascertainment of data from multiple sources: maternal HIV clinic, prenatal, labor/delivery, newborn and pediatric records, standard case report form and supplemental data collection form, active follow-up of exposed infants every 6 months for infection status
- Collaboration with programs (HIV prevention, MCH, substance abuse)

States Without HIV Surveillance

- Alternate methods to collect data on HIV-infected mothers and their newborns—facility-based collection of enhanced perinatal HIV surveillance data, with Institutional Review Board (IRB) approval at those facilities
- Standard case report form and supplemental data collected on HIV-infected mothers and exposed children at those selected facilities (prenatal care, HIV testing, ART)

- Ascertainment of data on perinatal AIDS cases—reasons for failures statewide
- Collaboration with programs (HIV prevention, MCH, substance abuse)

Characterizing the Local Perinatal HIV Epidemic and the Impact of Prevention, Using HIV and All Available Sources of Surveillance Data

- Prenatal care
- General population [birth certificates, Pregnancy Risk Assessment Monitoring System (PRAMS)]
- HIV-infected women (enhanced perinatal HIV surveillance)
- HIV counseling and testing
- All pregnant women (birth certificates, PRAMS, audit of hospital prenatal records at EIP sites)
- HIV-infected women (enhanced perinatal HIV surveillance)
- Use of antiretroviral therapy—ART, enhanced perinatal HIV surveillance, Survey of Childbearing Women (SCBW)
- Outcome of child (enhanced perinatal HIV surveillance)
- Other sources [Medicaid, Supplement to AIDS Surveillance (SHAS), HIV counseling and testing, PSD]

General Perinatal HIV Prevention Surveillance Data

- The number of women living with AIDS is increasing, from 15% (1992) to 20% (1998). The number of women ages 15-34 living with HIV infection is up to fivefold higher than the number living with AIDS in some areas, based on HIV surveillance data.
- The epidemic has especially affected minority populations.
  AIDS cases in adult/adolescent women (N = 10,998) rates per 100,000 by race/ethnicity

White, not Hispanic	= 2
Black, not Hispanic	= 50
Hispanic	= 17
Asian/Pacific Islander	= 1
American Indian/Alaska Native	= 4

- The Survey of Childbearing Women (SCBW) estimated that 6,000-7,000 HIV-positive women deliver infants each year in the United States.
- In order for a prevention success to occur, an HIV-positive woman has to be in prenatal care, be offered and accept HIV counseling and testing, be offered and accept ZDV, adhere to the regimen, and receive follow-up care for herself and her baby.
- The number of perinatally acquired AIDS cases increased from 1989 until a peak in 1992, then declined rapidly after 1994 (ACTG 076), with a 74% decline from 1993 to 1995.

The question is: Can more cases be prevented? Let's look at examples of enhanced perinatal surveillance data.

Selected Surveillance Findings, by Project

STEP. Original STEP data from NJ, LA, SC, MI were critical for the Institute of Medicine (IOM) report and many prevention programs.

- Compared with the SCBW, enhanced perinatal surveillance ascertained over 85% of the estimated mother-infant pairs, which is a very complete surveillance system.

- Prenatal care was found to be less commonly received by HIV-infected women diagnosed during pregnancy (2%) than by the general population (15%).
- Prenatal care by race/ethnicity reflects the general population.
- 35% of HIV-infected women who used illicit drugs during pregnancy did not receive prenatal care compared with 6% who did not.
- Lack of prenatal care during the first pregnancy predicts lack of prenatal care in subsequent pregnancies, according to data in STEP.
- In Connecticut, many HIV-infected women who did get prenatal care received very few visits; 82% of the HIV-positive women received their prenatal care in a clinic and only 4% in private offices.
- The proportion of HIV-infected women tested before delivery was 68% in 1993 and increased to 81% in 1996.
- Proportions of HIV-infected women receiving prenatal, intrapartum, and neonatal ZDV increased dramatically from 1993 to 1996. Very few (<5%) refused ZDV when offered.

Other Findings from Perinatal HIV Surveillance Data in 32 States

- Of children born to HIV-infected mothers and reported to CDC in 1998, the mother was tested before or at birth in only 34% of children with perinatally acquired AIDS, compared with 89% of HIV-exposed children and 61% of HIV-infected children.
- Increasing numbers of mothers who were tested for HIV before the child's birth received any ZDV—over 85% among births in 1998—and increasing numbers of women are receiving other ART in pregnancy—almost 40% in 1998.
- Data from Louisiana highlighted that most HIV-infected women who received prenatal care also received some form of therapy. Prenatal care and ZDV use are associated.
- Data from South Carolina showed that an STD diagnosis during pregnancy or illicit drug use during pregnancy are predictors of receipt of ZDV; thus, STD clinics may be a target for prevention activities in some areas.
- The proportion of HIV-infected children decreased dramatically from 1993 to1997.
- Data from special perinatal HIV surveillance project in New York City indicate that only 7% of children born to mothers who received ZDV prenatally were HIV-infected children compared with 21% born to those who did not.
- Data from NYS indicate that intrapartum and newborn ZDV prophylaxis may be protective as well.

Pregnancy Risk Assessment Monitoring System. PRAMS is a CDC-funded population-based surveillance system of women giving birth. It is administered through the Division of Reproductive Health, covering not only HIV but other risk factors as well. Once in prenatal care, a woman needs to be offered and accept HIV testing. In 1996, the percent of women who in 11 states discussed HIV testing with a health care worker ranged from 60% to 84%. Once offered, most accepted. By 1998, trends in HIV counseling and testing increased, significantly in some states. Prenatal HIV test counseling in seven states increased from 69.7% in 1996 to 77.6% in 1998.

Behavioral Risk Factor Surveillance System. BRFSS is a CDC telephone survey of adults 18 years and older, conducted from 1994 through 1997. Among pregnant women, the proportion tested in 1996 (53%) was significantly higher than in 1995 (41%); there was no significant change from 1996 to 1997. Among women who were not pregnant, there was no change over time.

Connecticut

- Data from perinatal HIV surveillance indicate that not only do pregnant HIV-infected women tend not to receive prenatal care; but the care, once received, is not adequate. Almost 50% of HIV-infected women have fewer than 10 prenatal care visits. Source of care: Most (83%) received prenatal care in hospital-based clinics, making them a place for targeted education efforts.
- Data from a chart review of prenatal care records showed that more women are tested for other infectious diseases (hepatitis B, syphilis, rubella) than for HIV and that HIV testing varies considerably from hospital to hospital.

Perinatal Guidelines Evaluation Project. Reasons for not accepting HIV testing during pregnancy (396 women, 1997)

Reason	Percent
No perceived need for test	42
Previously tested	30
Not asked or test not recommended	8
Other	7
Not ready, too scared	4
Partner HIV-negative	2
Fear of discrimination	1
Scheduling conflict or delivered before test could be performed	2

Epidemiologic Profiles

Surveillance data can be used to create a perinatal epidemiologic profile, which enables one to examine what's going on in communities and target programs, follow programs, and change programs.

- Provide an understanding of the HIV epidemic among populations in the planning region (number of cases, rates, distribution).
- Characterize populations at risk for HIV infection.
- Provide a scientific foundation for the planning process and subsequent steps.
- Perinatal surveillance benefits women's health in general, as the data are applied to other perinatal infectious diseases; e.g., hepatitis B, syphilis, group B streptococci.

Potentials and Challenges for Eliminating Perinatal HIV Transmission in the United States

- Increasing receipt of prenatal care by HIV-positive women, especially substance-users
- Making HIV counseling and voluntary testing the standard of care among all prenatal care providers
- Implementing rapid HIV testing at the time of labor and delivery
- Monitoring the emergence of antiretroviral resistance
- Potential toxicities of antiretroviral drugs
- Improving adherence to complex ART regimens, especially among adolescent women
- Perinatal surveillance to target and evaluate interventions not available in all states

Update on Perinatal HIV Research — Mary Glenn Fowler, CDC

- **Perinatal transmission is the primary route of HIV infection in infants and children.**
- **Transmission rates globally vary from 14% to 35–40% in the absence of antiretroviral therapy, and from 2% to 10% with antiretroviral therapy.**
- **Transmission rates almost double in breast-feeding settings.**
- **Worldwide, approximately 1600–1800 infants are infected each day (almost 600,000/year).**
- **Lessons learned in the United States are being applied internationally.**

Questions for Discussion

1. **What are the risk factors before and after Pediatric AIDS Clinical Trials Group (PACTG) 076?**
2. **What do we know about breast-feeding transmission?**
3. **What do the trials tell us?**
4. **What are CDC perinatal activities?**

1. What are the risk factors before and after Pediatric AIDS Clinical Trials Group (PACTG) 076?

- **Increased illness severity (including immune factors)**
- **Maternal drug use**
- **Low vitamin A levels, anemia (international settings)**
- **Preterm delivery**
- **Breast-feeding**
- **Unrelated to maternal age, race/ethnicity, or previously infected child**

Persistent Maternal Risk Factors for Transmission

- **Viral load (U.S. PACTG 185, Thai Bangkok study). All studies to date find a general relationship of increased maternal viral load and risk for perinatal HIV transmission. The zidovudine regimen appears to be protective at all levels of maternal RNA (ACTG 076 findings). Most studies do not find a threshold below which no transmission occurs, although most recent studies show an extremely low risk when viral load isl undetectable.**
- **Vaginal delivery or not receiving elective cesarean section. Meta-analyses and randomized trial showed elective cesarean section is associated with 50% reduction of risk for transmission.**
- **Duration of membrane rupture. PACTS, ARIEL studies showed that prolonged membrane rupture (>4 hours) doubles the risk for infant HIV infection.**
- **CD4 count? Maternal CD4 counts were important risk factors before PACTG 076; lower CD4 counts have been associated with increased perinatal transmission. Data from Kenya suggest that women whose human leukocyte antigen (HLA) type was most similar to their infant's have increased risk of transmission. Polymorphisms in the regulatory regions of CCR5 may also influence transmission.**
- **Chorioamnionitis? Chorioamnionitis increased the risk for transmission in some studies—Zaire, PACTG 185, ARIEL—but not all.**
- **Preterm delivery? A French study of 1,632 infants found a number of obstetrical factors—e.g., sexually transmitted diseases, preterm delivery—were related to risk of infant HIV infection.**

2. What Do We Know about Breast-feeding Transmission?

- **A Nairobi trial suggests breast-feeding increases risk for transmission in the first weeks of life, with 2/3 of all breast-feeding transmission occurring by 6 weeks and 3/4 by 6 months.**
- **Late breast-feeding has a low continuous risk of 3.2% per year.**
- **Risk factors in breast milk include high viral load; other factors may include mastitis and low HIV immunoglobulin A (IgA) levels in breast milk.**
- **Exclusive breast-feeding may have a protective effect.**

3. What Do the Trials Tell Us?

International trials were based on the information from the 1994 U.S. AZT trial, Pediatric AIDS Clinical Trials Group (PACTG) 076 (50% reduction in transmission). Because this complicated regimen might not be feasible in many parts of the world, international trials examined shorter regimens focusing on different time periods of administration.

International Trials

- **Nevirapine. Uganda phase I, IIB trials showed efficacy of nevirapine is 47%, relative to that of AZT.**
- **AZT/3TC. PETRA results from Africa and multicountry trials showed**
  - **Arm A —Prenatal AZT/3TC efficacy in the last month suggests slightly better results than short-course AZT alone (50% vs. 37%).**
  - **Arm B —Intrapartum/postpartum AZT/3TC efficacy is similar to short-course AZT (37%).**
  - **Arm C— Intrapartum AZT/3TC alone was similar to placebo, suggesting that prophylaxis just during labor is not sufficient.**
- **AZT short-course therapy (Côte d'Ivoire, Burkina Faso, Thailand). Efficacy was better in non–breast-feeding settings (Thailand 50%) than in breast-feeding settings (West Africa 37%). There was no obvious added benefit of giving postnatal 1-week AZT to mothers in West Africa and little loss of efficacy of short-course AZT through the first 6 months.**
- **Neonatal prophylaxis. Neonatal nevirapine or AZT/3TC in labor through the first week of life substantially reduces transmission in breast-feeding settings (PETRA and HIVNET 012). Intrapartum AZT/3TC prophylaxis alone is not sufficient, nor is AZT intrapartum and to the neonate for 1 week in breast-feeding settings. Data from New York City suggest that 6 weeks of neonatal AZT can be effective in non–breast-feeding settings. The duration of prophylaxis needed in breast-feeding settings is unknown.**

Other Nonantiretroviral Perinatal HIV Clinical Trial Results

- **1994 Malawi chlorhexidine trial showed no difference in transmission rates for vaginal cleansing/neonatal wash vs. no therapy.**
- **1998–99 vitamin A trials in Malawi, South Africa, and Tanzania showed no effect on transmission.**
- **1999 Kenya trial showed significant reduction (44%) in transmission for formula-fed vs. breast-fed infants.**

- **1998 European elective cesarean-section trial showed a 50% reduction in risk for transmission compared with other types of delivery.**

4. What are CDC perinatal activities?

Current CDC Domestic (U.S.) Activities

- **Mother Infant Rapid Intervention at Delivery (MIRIAD)—rapid testing for late-presenting women**
- **Follow-up of perinatally exposed infants—Pediatric Spectrum of Disease (PSD), PACTS**
- **Congressional funding to maximally reduce perinatal transmission in high prevalence states**
- **Pediatric state HIV surveillance**

Current CDC International Activities

- **Short-course AZT trials (Thailand and Côte d'Ivoire)**
- **Pooled analyses of late HIV transmission at 12 and 18 months (CDC and ANRS)**
- **Breast-feeding laboratory studies (Côte d'Ivoire and Uganda)**
- **Pilot studies of rapid testing and counseling (Uganda, Botswana, South Africa)**
- **Short-course AZT/formula pilot studies in Africa (CDC and UNAIDS/UNICEF)**

Potential Future CDC International Activities

- **Pilot studies of opportunistic infection prophylaxis for HIV-infected children in resource-poor settings**
- **Collaborative efforts with other groups to carry out antiretroviral trials during the breast-feeding period**
- **Perinatal vaccine trials (uninfected women postpartum and HIV-exposed infants)**

Summary

- **The most critical risk factors since PACTG 076 are viral load and breast-feeding.**
- **The clinical trials indicate usefulness of viral load reduction and neonatal prophylaxis.**
- **Pressing future international challenges**
  - **Strategies for breast-feeding treatment**
  - **Implementation of trial results**
- **CDC is working to maximally reduce perinatal HIV transmission in the United States and internationally.**

Panel of National Organizations

American College of Obstetricians and Gynecologists (ACOG)—Debra Hawks

ACOG is a specialty society with about 40,000 members who deal with women's health issues and infant and child health. ACOG members comprise almost all board-certified obstetrician-gynecologists in this country and participate in the bulk (about 85%) of the deliveries in the United States each year; family physicians and nurse midwives make up the other 15%. ACOG delivers committee opinions to respond quickly to fast changes in practice (data, technology, devices). Recent examples include a committee opinion on Pediatric AIDS Clinical Trials Group (PACTG) 076. Another committee opinion was issued in 1999, showing that scheduled cesarean delivery at 38 weeks can further reduce perinatal HIV transmission, depending on the woman's viral load and medical status. The 1999 revised AAP/ACOG policy statement on the IOM report recommends universal perinatal HIV testing with patient notification, but with the proviso that counseling and education to pregnant women is still important but should not be a prerequisite or a barrier. The Institute of Medicine (IOM) projects that if 100% of obstetricians and gynecologists (ob-gyns) offered testing to pregnant women and 100% of the women accepted, the number of HIV-infected babies would be reduced by 33% (386 babies/year). ACOG's goal is to increase routine HIV testing by ob-gyns (currently offered by 50–75%), focusing on those who do not recommend testing because they either do not perceive their patients to be at risk, do not have sufficient time, or are limited because of pretest counseling requirements.

There has been a significant decline in pediatric AIDS cases; however, there still is a need to increase routine HIV testing of all pregnant women. Many women are getting tested during pregnancy, according to the IOM report, and testing is greatly affected by how the provider presents the information to the women and encourages them to be tested. We see less testing in private populations than in public clinics or areas of high HIV prevalence. There is a reason for this lack of testing. Probably the legal pretest counseling requirements that most states have are the biggest barriers. Ob-gyns are obligated to comply with these state-mandated counseling requirements. Women are largely receptive to HIV testing and will do most anything to improve the health of their infants. IOM has shown some statistics on how much of an impact increased testing could have on reduction of pediatric AIDS cases.

ACOG has a grant from CDC to focus on perinatal HIV. The bottom line is to further routinize prenatal HIV testing, through a number of mechanisms.

- **Distribute patient and professional materials**
- **Issue AAP/ACOG statement on testing**
- **Issue cesarean delivery committee opinion**
- **Design innovative physician tools on testing (tear pad to give clients, physician reference sheet)**
- **Provide postgraduate education (annual clinical meeting, postgraduate courses)**

- **Promote perinatal HIV testing at grassroots level (in all 10 districts)**
- **Enhance media coverage (to heighten consumer—male and female — interest in testing)**
- **Participate in state-specific Providers Partnership (CT, NC), specific to perinatal HIV**
- **Collaborate with AAP and others**
- **Evaluate project (survey 1,000 U.S. ob-gyns on testing practices, risk perception, reasons for not testing all pregnant patients)**

This spring ACOG will be disseminating materials to every ACOG fellow and making them available to other organizations as well. They will be directly mailed to every state health director, every state MCH director, and every state AIDS director. Before and after the mailing, 1,000 ob-gyns will be randomly sampled to evaluate whether these materials have affected ob-gyns' testing practices, risk perceptions, and to assess reasons for not routinely testing all pregnant patients.

Materials Available

- G **Committee Opinion, Scheduled Cesarean Delivery and the Prevention of Vertical Transmission of HIV Infection**
- G **Joint Statement of ACOG/AAP on HIV Screening**
- G **Patient education pamphlet, *HIV Testing & Pregnancy* (under revision)**
- G **Video, *HIV & Pregnancy***
- G ***Important News for Pregnant Women* (tear sheet adapted from Alberta Health)**
- G **Physician reference card (adapted from Alberta Health)**

Contact Information

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American Academy of Pediatrics (AAP) —Alicia Siston

The AAP is a not-for-profit professional organization with a membership of approximately 55,000 pediatricians. The AAP's goals are to develop policies and programs in five specific areas: advocacy, education, research, service, and improving the systems through which pediatric care is delivered.

The AAP believes that pediatricians play a vital role in the further reduction of perinatal HIV transmission. Through its Committee on Pediatric AIDS, the Academy has issued several policy statements to its members covering such topics as perinatal HIV infection and testing, HIV transmission through breast-feeding, education of children with HIV, and evaluation and medical treatment of HIV-exposed infants. All policy statements are available on the website.

Education—The AAP will promote perinatal HIV prevention to its membership through the following:

- **A special "Perinatal HIV Prevention" insert in the AAP's standard batch mailing. The insert will include a cover letter highlighting the importance of pediatrician involvement, three patient education brochures, a poster from the Elizabeth Glaser Pediatric AIDS Foundation (PAF), and a fact sheet on this issue**
- **A reprint of the Executive Summary from the Institute of Medicine (IOM) Report, *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States,* in their news magazine, *AAP News***
- **Promotion of the IOM report and AAP/ACOG joint policy statement**
- ***AAP Grand Rounds*— an article in this monthly subscription newsletter**
- ***NeoReviews*—an article in this online section of *Pediatrics in Review***
- **Other educational courses and sessions (Practical Pediatrics CME, Pediatrics Review and Education Program, and the AAP Annual Meeting)**

Collaborations

- **ACOG. The AAP has collaborated with ACOG to revise a joint policy statement on HIV screening of pregnant mothers, "Human Immunodeficiency Virus Screening," published in the July 1999 issue of *Pediatrics.***
- **IOM. The AAP was represented on the IOM Committee on Perinatal Transmission of HIV, which produced the report, *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States.***
- **AHA. The AAP will attempt to involve the American Hospital Association (AHA) in efforts to educate patients and providers on issues surrounding perinatal HIV transmission and quality assurance.**
- **NAPNAP. Collaboration with the National Association of Pediatric Nurse Associates and Practitioners (NAPNAP) will facilitate access to health care providers who interact with families to determine appropriate strategies to inform and educate their membership on this topic.**

Membership Assessment—The AAP Department of Pediatric Practice will conduct a Periodic Survey of Fellows to evaluate the knowledge, attitudes, and behaviors of AAP members pertaining to the further reduction of perinatal HIV transmission. The Committee will carefully review the results and suggest mechanisms for how the AAP can continue to educate its membership on this topic in an effort to effect behavior change. AAP will work with ACOG and with the National Pediatric and Family HIV Resource Center to work out similar assessments of membership and compare with ob-gyn and family practitioner results. The AAP will mail out a survey to 1,600 Academy fellows; response rate is typically 70%. We are hoping to do a pre and post survey, but because the Academy only has the capacity to conduct four surveys a year, this may not be possible.

I'll now turn the floor over to Cathy Wilfert, who will discuss some of the exciting opportunities we hope to pursue with AHA.

Cathy Wilfert—I'm going to take just one more minute because I think we all believe in the importance of education. However, to change or encourage a change in behavior, it may be useful if one of the criteria by which provision of care is assessed is whether the offering of counseling and testing to all pregnant women occurs in the hospital setting where infants are delivered. Therefore, we would like to think optimistically that we can arrange discussions with our colleagues at ACOG and the AHA to have this incorporated as an essential standard of care.

At the same time, we have noticed a gap in the linkage of mother-infant charts. There is much information besides HIV that should be transferred automatically to the infant's chart. Whether we can accomplish this, we don't know; but it seems it should be beneficial to all of child health if those kinds of relevant information could be easily accessible and if we can agree that the uniform offering of counseling and testing is something that should be used as a standard of care assessment. Thank you.

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Association of Maternal and Child Health Programs (AMCHP) —Sarah Pfau

I'm here from Washington DC, representing AMCHP, a national nonprofit organization that provides leadership to assure the health of all women of reproductive age, children—including children with special health care needs—and youth. Its over 400 members include directors and staff of state MCH (Title V) programs and professionals in government, academia, research, policy, and advocacy. AMCHP develops position papers and policy statements, develops issue briefs and fact sheets, and monitors actions of Congress. We do a lot of policy analysis work; we also work with legislators at the state and national levels to ensure that policymakers are informed from the public health perspective about a variety of MCH population issues. We work with issues pertaining not only to perinatal and women's health but also adolescents, infants, and children with special health care needs.

In relation to our cooperative agreement with CDC, some of the things that AMCHP has done in the past include 1995 publications on HIV transmission prevention projects at the state level. In 1999, AMCHP revised its position statement on HIV counseling and testing. AMCHP promotes universal testing with counseling, with the understanding that state policies dictate the consent component of HIV testing. All of AMCHP's current position statements are accessible on our website: www.amchp.org. More broadly, AMCHP promotes the need for a continuum of care for women in addition to preconceptional and prenatal care.

AMCHP also has two other cooperative agreements with CDC (in the Division of Adolescent and School Health and the Division of Reproductive Health), and staff members serve on a lot of national coalitions. These activities provide insight into the work we will be putting into this cooperative agreement. Our primary goal in this cooperative agreement is to work with the state Title V programs to coordinate perinatal HIV transmission prevention efforts into their preconceptional, prenatal, and ongoing care for women. We also hope to provide technical assistance, communications, and the dissemination of information that will be valuable to Title V programs. We are conducting a survey that will be released to MCH directors within the next few weeks. The survey assesses the current status of standards, practices, policies, and laws across states as well as state collaborative efforts and how they are funding their perinatal HIV transmission prevention efforts. We encourage collaboration between the Title V programs and the Ryan White Title IV, Title X programs, AIDS directors, and others, and the building of networks to ensure comprehensive care.

Forums. AMCHP communicates and provides technical assistance through

- **Annual meetings**
- **Bimonthly newsletters, *Updates***
- **Website (www.amchp.org)**
- **National audio conferences**
- **Policy publications**
- **Participation in Title V regional conference calls**
- **Collaboration with many national organizations and federal agencies**

Objectives. AMCHP's broad objectives include

- **Providing technical assistance and disseminating materials to promote perinatal HIV prevention within the MCH sector**
- **Assisting state Title V programs in integrating HIV counseling and testing into routine preconceptional and prenatal care**
- **Facilitating the exchange of ideas and experiences in perinatal HIV transmission prevention programs among state Title V programs and key agencies within the states**

Title V is administered by the Maternal and Child Health Bureau (MCHB) of HRSA, with whom AMCHP works closely. Title V services and their target populations make them ideal constituents for AMCHP. Authorized under the Social Security Act of 1935, Title V became a block grant as of 1981. The only federal program solely devoted to improving the health of all mothers and children, it serves over 20 million women, children, and families per year. Title V provides wraparound MCH services to underinsured, uninsured, and publicly insured families. Title V services are unique because they include the core public health functions of assessment (data, evaluation, research), policy development (standards, guidelines, model programs), and assurance (regulation, monitoring, technical assistance, support services). Title V coordinates and integrates population-based services to avoid fragmentation and duplication in meeting families' needs.

Title V Perinatal HIV Prevention Efforts. The existing Title V efforts for prevention of

perinatal HIV transmission include

- **Educating and training providers**
- **Informing consumers**
- **Developing counseling and testing protocols**
- **Developing and monitoring negotiated state performance measures specific to HIV/AIDS**

Plans. The AMCHP cooperative agreement, in the context of existing Title V perinatal transmission efforts, plans in the first year to do the following:

- **Survey all state Title V programs (MCH directors) to provide a source of very specific information about the current status of both state and Title V program policies and practices regarding HIV testing and counseling of pregnant women.**
- **Publish a monograph on the results of the survey.**
- **Convene a consensus workgroup of Title V representatives from the 10 public health regions.**
- **Develop policy recommendations based on the survey and workgroup.**
- **Convene an expert panel with representatives from various national organizations and federal, state, and local agencies.**

AMCHP's 1995 position statement on HIV testing and counseling was brief, supporting voluntary testing. As a result of the recent IOM guidelines, the revised position statement is more comprehensive, supporting the goal of universal counseling and testing for all women—especially pregnant women.

Materials Available

- G **Organizational position statement on HIV testing**
- G **Title V information**
- G **AMCHP information**
- G **Publications list**

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National Pediatric and Family HIV Resource Center (NPHRC)— Carolyn K. Burr

NPHRC has a plan for reducing perinatal HIV transmission through targeted training of health care providers in four states. The NPHRC is a project within the François-Xavier Bagnoud Center at the University of Medicine and Dentistry of New Jersey (UMDNJ).

The organization provides hands-on education, technical assistance, and consultation to programs and providers; forms expert working groups on emerging issues; develops and distributes provider and consumer educational materials; and provides online education. The

NPHRC website is linked to many related sites.

NPHRC's project goals for targeted training are as follows:

- **Increase providers' knowledge about HIV counseling and testing of pregnant women.**
- **Increase providers' understanding of strategies to reduce perinatal HIV transmission.**

How do you best achieve those goals? Educating providers about HIV raises some special issues. Early in the epidemic, providers had negative attitudes about caring for people with HIV and AIDS. More recently, professionals, especially younger ones, are showing an increasing willingness to care for persons with HIV. As HIV testing of pregnant women becomes more universal, more providers who may be reluctant to care for patients with HIV or may not believe their patients are at risk will be expected to offer HIV education and testing to their patients.

NPHRC plans to build upon what they did in New Jersey to promote the findings of the PACTG protocol 076. Over the next two years, NPHRC will partner with key organizations within four states. One-day training in each state will use a train-the-trainer, or faculty training, (practicing clinicians) approach to build on existing expertise and resources. The training will use didactic (familiar to physicians) and interactive (most likely to modify behavior) approaches. The content of the training will include

- **HIV counseling and testing in pregnancy, including test interpretation**
- **Medical management of HIV in pregnancy**
- **Reduction of perinatal HIV transmission**
- **Controversies in perinatal HIV care**
- **Adult learning strategies**

Enabling strategies will involve providing materials that facilitate adaptation to change; e.g., patient education materials and provider pocket guides. Trainers will not need to develop their own materials but rather will be given materials that provide a mixed didactic and interactive approach. Trainers will receive a complete curriculum of slides, case studies (interactive), patient and provider educational materials with which they can then educate a larger audience of women's health care providers and provide ongoing expertise within the community. Follow-up (6–9 months) surveys will evaluate trainers' knowledge and attitudes about perinatal HIV infection and their practices regarding HIV testing of pregnant women. The outcome of the training can be measured by the number of women receiving HIV testing and the number of HIV-exposed infants before and after training intervention.

Materials Available (in English and Spanish)

Materials will be updated after revised perinatal guidelines are published.

- **Pocket card:** ***Guidelines for Use of HIV Antiretroviral Therapy in Pregnancy/Follow-up Care for Infants Born to Mothers with HIV Infection***
- ***Reduction of Perinatal HIV Transmission: A Guide for Providers***
- ***What Women Need to Know: The HIV Treatment Guidelines for Pregnant Women***

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CityMatCH—William Sappenfield

I am actually with CDC, assigned to CityMatCH. The CityMatCH mission is to enhance the ability of health departments at the local level to improve the health and well-being of children and families in urban areas. CityMatCH has a unique infrastructure designed to promote communication and collaboration across the 150 urban health departments (city, county, regional, district, state) whose jurisdictions include one or more of the 200 largest U.S. cities. CityMatCH is a hybrid entity that is both an applied research organization based at the University of Nebraska Medical Center and a free-standing national membership organization of health departments' maternal and child health (MCH) programs and leaders representing urban U.S. communities. *Preventing Perinatal Transmission of HIV in U.S. Cities* is an Association of Teachers of Preventive Medicine (ATPM) cooperative agreement between CDC and CityMatCH.

CityMatCH offers

- **Effective existing infrastructure for communication and information dissemination**
- **Capacity building targeting urban health departments and their community partners, including**
  - **Urban MCH Data Use Institute. This year-long training Institute focuses not just on data but on effective data use. Community-based teams of policy makers, program managers, and data specialists meet face to face for skills building opportunities three times a year and undergo distance training five times a year. In addition, teams receive mentoring in carrying out locally based projects. The goal is twofold: increasing health department capacity for using data effectively, and creating change in the health department's use of data in decision making and execution of its core functions. Individual skills development is only a step toward the goal.**
  - **Work Group on Urban Maternal and Child Health Assessment (GUMCHA) Learning Clusters. These learning groups, organized and facilitated by CityMatCH, combine scientific experts and public health practitioners from selected cities to translate data and research into effective practice and policies. Focusing on a public health issue (e.g., infant mortality, perinatal transmission of HIV) or assessment method, the Learning Clusters jointly identify strategies to develop, use, and/or disseminate new methods or approaches to prevention within and across their cities.**

To determine a baseline of local health department involvement in perinatal HIV prevention in U.S. cities, CityMatCH sent a two-page rapid fax query to its member urban health departments in May of 1999. The survey assessed current level of engagement in HIV prevention and perinatal HIV-related activities. Perinatal HIV was acknowledged as a problem, but the

responses from the membership varied. CityMatCH responded with the following call to action:

- **Perinatal HIV transmission predominantly occurs in U.S. cities; accordingly, its reduction requires an urban strategy.**
- **Current urban health department involvement is diverse in type and depth. While work is occurring, it is frequently fragmented and therefore insufficient to completely prevent perinatal HIV infection.**
- **CityMatCH has useful experience and expertise to offer. Its members' needs are diverse; this cooperative agreement will enhance capabilities.**

In order to further reduce perinatal HIV transmission, the following shifts must occur:

- **Shared state-urban public health accountability**
- **Population-based systems of coordinated, universal perinatal prevention**
- **Coordinated systems for prenatal outreach and perinatal care**
- **Integrated team-based learning and problem-solving in communities**

The CityMatCH Plan

Goal #1. Promote learning across states and urban communities with the highest concentrations of perinatal HIV transmission to identify more effective, sustainable approaches to assessment and prevention.

Approaches

- **Use Learning Clusters (cities, expertise, and resources) for urban perinatal HIV prevention.**
- **Identify urban-specific prevention strategies.**
- **Promote peer exchange and technical assistance.**
- **Achieve measurable results in HIV screening outreach.**

Actions: Over the next three years, we will establish two Learning Clusters for the prevention of perinatal HIV.

In Learning Cluster 1, selected city teams and invited experts together will decide whether to develop comprehensive strategies vs. a specific issue-focused approach. Learning Cluster 2 will either refine and expand on what was learned from Learning Cluster 1 or may be a more in-depth implementation of interventions and best practices.

Goal #2. Inform and engage urban health department programs and leaders in the prevention of perinatal transmission of HIV/AIDS. Types of information to be shared will include basic and clinical sciences; HIV surveillance, assessment, and prevention information; and successful strategies.

Actions

- **Develop community-based HIV prevention products and processes.**
    - **Approaches to planning**
    - **Guidelines for community-oriented strategies**
    - **Descriptions of best practices**

- **Urban public health leadership development**
- **Better integration of MCH and HIV programs**
- **Comprehensive strategies to decrease fragmentation in the public health community**
- **Capacity building of public health agencies to carry out strategies**

- **Disseminate information via website (www.citymatch.org), Fax Alerts to members, mailings to members, and the materials listed below.**

Selected Materials Available

- **Quarterly newsletter, *CityLights***
- **CityMatCH annual Urban Leadership Conferences**
- ***DUInfo,* description of Data Use Institute**
- **Electronic NewsBriefs (biweekly)**

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Plenary Session Day 2

Wednesday, January 12, 2000

Perinatal HIV Transmission Grantee Meeting

Atlanta Marriott North Central
2000 Century Boulevard, NE
Atlanta, Georgia
January 11–12, 2000

Wednesday, January 12
Moderator— Sam Dooley, Centers for Disease Control and Prevention (CDC)

Sam Dooley welcomed participants and opened the meeting on January 12 at 8:30 A.M.

Update on Revised United States Public Health Service (USPHS) Policy on HIV Screening of Pregnant Women and Treatment of HIV-Infected Pregnant Women — Martha Rogers, CDC

Good morning. The national guidelines for prevention of perinatal transmission are actually in two different documents; both are part of the MMWR Recommendations and Report series: guidelines for counseling and HIV testing of pregnant women, last published in 1995, and prophylactic treatment for women who test positive during pregnancy, second revision in 1998. Both are currently undergoing yet another revision; neither is out yet. So my talk will be in generalities.

I will begin by giving you some history about the screening of pregnant women, pointing out the evolution of policy over time.

Evolution of Policy for HIV Screening of Pregnant Women
1985—An HIV antibody test became available. CDC published the first recommendations for prevention of perinatal HIV transmission. We knew very little at that time about transmission and had little to offer pregnant women. Recommendations at that time were targeted and not very effective.

- **Counseling and testing should be offered to women at high risk.**
- **HIV-infected women "should be advised to consider delaying pregnancy until more is known" and advised against breastfeeding.**

1994—Pediatric AIDS Clinical Trials Group (PACTG) 076 results were announced. USPHS published recommendations for prophylactic treatment of HIV-infected pregnant women.
1995— USPHS published revised recommendations for HIV counseling and voluntary testing of pregnant women. The recommendation moved away from a targeted approach and more toward a universal approach, recommending that "health care providers ensure that all pregnant women are counseled and encouraged to be tested for HIV . . ." and that testing should be voluntary, not mandatory.
1996—Combination therapy with protease inhibitors became widely available and had a tremendous effect on quality of life for infected persons.
1998—USPHS published revised prophylactic treatment guidelines for use of antiretroviral (ARV)

agents (including combination therapy) during pregnancy for maternal health and reduction of perinatal transmission of HIV.
1999—As a result of being commissioned by Congress (as part of the last Ryan White reauthorization) to evaluate how well CDC and other federal agencies and state health departments were doing in reduction of perinatal HIV transmission, the Institute of Medicine (IOM) published a report recommending a "national policy of universal HIV testing, with patient notification, as a routine component of prenatal care." Consent was also simplified to an opt-out or right-of-refusal approach. New findings about short-course therapy and therapy at the time of labor and delivery and to the newborn added support to the treatment recommendations.
2000—USPHS plans to publish revised guidelines for HIV screening of pregnant women and for treatment.

Controversies Around Policy for HIV Screening of Pregnant Women

- **Pregnant women and newborns are often considered "vulnerable" populations, especially in terms of research and medical procedures.**
- **There used to be a conflict between women's rights and infant's rights, when testing was considered good for the infant but not necessarily good for the woman. However, new treatment options are enhancing the testing benefits for both.**
- **Policy was sometimes seen to be disrespectful and demeaning of women by treating them as vessels for reproduction and vectors for transmission. A lot of attention was needed to balance the benefits to the woman as well as to the infant.**
- **Financing and cost-effectiveness was a big issue, especially for low-prevalence areas. This concern may still exist.**
- **Changes in the informed consent process for HIV testing have raised concern that the consent process is "eroding." The move toward right of refusal may mean that women get less counseling and are less aware of some of the risks. However, benefits have greatly increased but must still be weighed against the risks.**
- **The IOM request for simplification of counseling has raised concern over the role of counseling: Where does counseling fit in? How long should it be? Who should deliver it? How should it be delivered?**

New Advances in Science and Technology Since Publication of Original Guidelines

- **More effective treatment for infected persons**
- **Proven effective prophylactic therapy for women at the time of delivery**
- **Increasing evidence for effectiveness of postexposure prophylaxis, especially with newborns**
- **Improved testing technology (e.g., rapid tests)**
- **Several studies indicating that women with undetectable viral loads transmit very rarely**
- **Better protection against discrimination (e.g., Americans with Disabilities Act)**

Lessons Learned from Evaluation of Current Policy and Putting Programs into Place

- **Testing is highly accepted when strongly recommended by provider.**
- **Lack of prenatal care is a big problem, especially among substance-abusing women.**
- **Some women decline testing, and some providers decline to offer testing because they perceive low risk.**
- **Logistics may sometimes be a problem.**

- **Adherence to complex treatment regimens can be difficult.**
- **IOM finds that some providers perceive counseling as a barrier to providing testing.**

Themes and Directions for Revised Guidelines

- **Emphasis will be on testing as a routine part of prenatal care.**
- **The testing process will be simplified (with the provision of minimal information).**
- **More extensive counseling ("prevention counseling") is not necessarily linked to testing but is recommended as part of routine education of pregnant women.**
- **Testing remains voluntary, but right-of-refusal type of consent is permitted.**
- **The consent process is flexible by permitting right of refusal but not recommending against more traditional informed consent. Written consent will not be mandatory in the new guidelines, although some state laws still require it. Ideally, HIV testing would be more like other prenatal disease screening.**
- **Providers should explore and address reasons for refusal of testing.**
- **More emphasis should be placed on testing and treatment at time of delivery for women without prenatal care.**
- **Testing of the newborn is recommended if the mother has not been tested, but testing is not mandatory if the mother refuses.**

Update on Prophylactic Treatment Recommendations and Other Interventions

- **The last document (published in 1998) took combination therapy into consideration.**
- **Other adult and pediatric treatment guidelines are dynamic documents and are maintained on the internet.**
- **An expert panel was formed in December 1999 to revise prophylactic treatment guidelines for pregnant women.**
- **This dynamic document will be available on the internet sometime in 2000.**
- **Immediate issues to be addressed by the panel:**
    - **What is the best treatment at time of delivery for women without prenatal care? Nevirapine? Zidovudine? Combination therapy? Other drugs?**
    - **What should mode-of-delivery recommendations be? We need to explore the value of cesarean delivery in women with very low viral loads.**

Remaining Issues for Consideration

- **ARV toxicity and long-term effects on children**
- **Need for more licensed rapid tests. Need two rapid tests to approximate the reliability of enzyme-linked immunosorbent assay and Western blot tests.**
- **Mode of delivery recommendations**
- **Treatment at time of delivery recommendations**
- **New Ryan White authorization around perinatal HIV transmission**

Again, the themes, especially around counseling and testing and screening, are in draft form and may vary in final form.

Contact Information

Website: www.cdc.gov/hiv/projects/perinatal

Health Resource Service Administration (HRSA) Programs for Pregnant Women and Children, Maternal and Child Health Bureau (MCHB) — Karen Hench, MCHB, HRSA

I want to acknowledge and thank the CDC staff for convening this very important meeting.

Just to briefly reorient you, HRSA is one of the 12 agencies within the Department of Health and Human Services. It ranks third in total federal appropriations and second only to the National Institutes of Health (NIH), if we consider only the Public Health Service (PHS) agencies. On behalf of Dr. Peter van Dyck, Associate Administrator of the MCHB, I'm here today to present the perinatal programs for women and their children, administered by MCHB, one of the four bureaus of HRSA. Within the MCHB, there are five divisions and four offices. These divisions and offices administer the various MCHB programs.

MCHB Perinatal Programs

Mission. The mission of the MCHB is to provide national leadership and to work in partnership with states, communities, public and private partners, and families to strengthen the MCH infrastructure, assure the availability and use of medical homes, and build the knowledge and human resources to assure continued improvement in the health, safety, and well-being of the MCH population.

Goals. MCHB has set the following goals for the year 2003, which are consistent with the Healthy People 2010.

- **To eliminate health disparities in health outcomes and removal of economic, social, and cultural barriers to receiving comprehensive, timely,and appropriate health care**
- **To assure the highest quality of care**
- **To improve the MCH infrastructure and coordinated system of care**

For each goal, eight to ten objectives have been developed to annually assess goal achievement.

Through MCHB, HRSA supports maternal and child health programs that

- **build health care and public health infrastructure**
- **explore innovations in care for children with special health care needs**
- **demonstrate and forge improvements in care for mothers and children**
- **expand emergency medical services for children**
- **promote abstinence among teenagers**

Budget. The MCHB appropriation in Fiscal Year 2000 is $873.5 million, a relatively small portion of the total HRSA budget, but its impact is far-reaching to the nation's mothers and children. A major component of the MCHB is Title V of the Social Security Act, which was enacted over 65 years ago. After the Omnibus Budget Reconciliation Act in 1981, Title V became the first state block grant program. It is a genuine partnership between the federal government, states, and local

communities to assure the well-being of women and children. Every four federal dollars are matched by three state dollars. Total MCH expenditures include income from MCH programs, local MCH funds, and other sources.

Populations served. The MCH population includes all U.S. pregnant women, infants, children, adolescents and their families, including women of reproductive age, fathers, and children with special health care needs.

Title V. In 1997, Title V programs served over 24 million persons. Almost 2 million of these were pregnant women, and an additional 1.8 million others, most of whom were nonpregnant women. Viewed a different way, of the nearly 4 million women giving birth in the United States in 1997, Title V served nearly 50% of them, mostly by providing prenatal or postnatal care services. The Title V block grant is the only federal program that focuses solely on improving the health of all mothers, adolescents, and children, whether insured or not, through a broad array of public health and community-based programs that are designed and carried out through well-established federal and state partnerships. The conceptual framework for these services is envisioned as a pyramid with four tiers of services and levels of funding that provide comprehensive services for mothers and children.

- **Direct health care, such as perinatal health services (47% of FY 97)**
- **Enabling services, such as transportation, outreach, and case management (25% of FY 97)**
- **Population-based services, such as newborn screening, counseling, education (14% of FY 97)**
- **Infrastructure building services, such as needs assessment, policy development, quality assurance (14% of FY 97)**

Performance measures. In accordance with the Government Performance and Results Act, MCHB has developed a set of 18 national "core" performance measures and up to 10 state-specific or negotiated performance measures that are based on priority needs as identified in their five-year statewide needs assessment. Resources are assigned and programs are designed around these priorities, and the programmatic activities are classified under one of four levels of the pyramid. An example of a national core performance measure is the percent of infants born to pregnant women receiving prenatal care beginning in the first trimester. Several states (e.g., AR, GA, MI, NH, TN) have identified state-specific priorities around prenatal HIV counseling, testing, and/or reduction of perinatal HIV transmission.

Title V Snapshot (data) book. In 1999, MCHB published a wealth of national and state-specific data from the 59 states and jurisdictions that submitted Title V applications in 1999 and 1997 annual data reports electronically. By going to your state's Fact Sheet, you can review the totals served and the total expenditures by individual category and your state's priority MCH performance measures.

- **85% of the Title V funds go directly to states.**
- **15% is a set-aside appropriated for Special Projects of Regional and National Significance (SPRANS) for special demonstration, research and training projects.**
- **12.75% is appropriated for the Community Integrated Services Systems (CISS), another set-aside to reduce infant mortality and increase the comprehensiveness of local service delivery systems.**
- **30% of state Title V funds within each state go to preventive and primary care for children**

and youth, and 30% is spent on services for children with special health needs.

Other MCHB Funding and Programs

- **Healthy Start ($90 million). Authorized under Section 301 of the PHS Act, the Healthy Start Initiative was founded in 1991 on the premise that community-driven strategies were needed to address the causes of infant mortality and low birthweight, especially among high-risk populations. During its first five years, one organizational intervention model and eight service intervention models were developed, including**
  - **community-based consortia**
  - **care coordination/case management**
  - **outreach and client recruitment**
  - **enhanced clinical services**
  - **family resource centers**
  - **risk prevention and reduction**
  - **facilitating services**
  - **training and education**
  - **adolescent programs**
- **Abstinence. Under Section 510 of the Social Security Act, $40 million is authorized for abstinence education for school-age children.**
- **Emergency Medical Services for Children (EMSC) ($17 million)**
- **Poison Control ($3 million, new for FY 2000)**
- **Newborn Hearing Screening ($3.5 million, new for FY 2000)**

Division of Perinatal Systems and Women's Health (DPSWH) Activities

- **Demonstration grants**
  - **Healthy Start (84)**
  - **Alcohol Screening During Pregnancy (4)**
  - **Perinatal Domestic Violence Intervention (4)**
  - **Innovative Approaches to Women's Health Promotion (3)**
- **Resource centers**
  - **Healthy Start (www.healthystart.net)**
  - **National Fetal and Infant Mortality Review (202.863.2587)**
  - **Women's and Children's Health Policy Center (410.502.5443)**
  - **National Center for Education in Maternal and Child Health (703.356.1964, www.ncemch.org)**
- **MCH provider partnerships**
  - **American College of Obstetricians and Gynecologists (ACOG). The MCH-ACOG partnership convened an expert panel in November 1999 to examine how changes in the nation's health care system have affected access to psychosocial services for pregnant women. A report on the findings will be published this year.**
  - **American College of Nurse Midwives (ACNM). These activities focus on provider education and perinatal health through provider partnerships in nine states.**
- **Mortality/morbidity review programs**
  - **Describe significant social, economic, cultural, safety, health and systems factors that**

contribute to mortality.
    - **Design and implement community-based action plans founded on information obtained from the reviews.**
- **Best practice guidelines and training**
    - **Bright Futures for Women**
    - **Perinatal Substance Abuse Prevention training and technical assistance**

Other Resources
- **Toll-free number for families to inquire about federally funded health care providers**
    - **1.800.311.BABY (English)**
    - **1.800.504.7081 (Spanish)**
- **Title V Data Reporting (www.mchdata.net)**

Summary

Title V and other MCHB programs are in a key position to reach high-risk, low-income women through HIV counseling, testing, and treatment programs. Across the country, and particularly in those states with the highest prevalence of HIV and AIDS among women of childbearing age and children, state Title V programs have responded to the epidemic with a range of interventions, including
- **incorporating HIV counseling and testing into prenatal care services**
- **developing guidelines and provider education for universal HIV counseling, voluntary testing, and use of perinatal antiretroviral chemoprophylaxis**
- **arranging for emergency coverage of zidovudine costs for newborns until enrolled in Medicaid**

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Health Resource Service Administration (HRSA) Programs for Pregnant Women and Children, HIV Programs —Lydia E. Soto-Torres, HRSA

HIV/AIDS Bureau (HAB) Services for Women and Children: The Ryan White CARE Act Programs for Women and Children

I will highlight in this presentation the HAB programs addressing the care needs of HIV-infected women and children. The HAB four priorities are

- **HIV/AIDS impacts diverse populations, including women and children.**
- **The quality of emerging HIV/AIDS therapies can make a difference.**
- **Economic changes of health care affect the HIV care network.**
- **Policy and funding are increasingly determined by outcomes.**

HIV/AIDS Bureau (HAB). HAB administers the Ryan White Comprehensive Act Resources Emergency Act. Dr. Joseph O'Neill directs the Bureau. HRSA and HAB are targeting efforts to provide HIV-infected women and their families a comprehensive circle of care. As previously mentioned, women have been seen as vessels of transmission. Most services have gone to men. In order to address the impact of the HIV epidemic in women, we, as partners, can work on providing and expanding that circle of care for women. As mentioned, HAB has four principles:

- **Addressing the epidemic**
- **Qualities of emerging HIV/AIDS therapies**
- **Economic changes of health care**
- **Policy and funding**

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act provides funding to states and other public or private nonprofit entities to develop, organize, coordinate, and operate more effective and cost-efficient systems for the delivery of essential health care and support services to medically underserved individuals and families affected by HIV disease. All the titles address the issues of women and children.

HRSA CARE Act: Programs

Title I: EMAs. Provides emergency relief funding to 51 Eligible Metropolitan Areas (EMAs).
Title II: States. Awards grants to all 50 states, the District of Columbia, Guam, Puerto Rico, and the Virgin Islands to improve the quality, availability and organization of HIV health care and support services. The AIDS Drug Assistance Program also is funded under Title II.
Title III: Early Intervention Services and Planning. Service grants support outpatient HIV early intervention services for low-income medically underserved people in existing primary care systems. Planning grants support communities and health care service entities in their planning efforts to develop high quality HIV primary care.
Title IV: Women, Infants, Children, and Youth. Programs focus on the development and operation of primary care systems and social services for women, infants, children, and youth

and link these care systems with HIV research and clinical trials. Focuses on continuum of care, from street outreach to long-term care.
Special Projects of National Significance (SPNS). Establish and test innovative demonstration projects that respond to the challenge of HIV/AIDS service provision to underserved and vulnerable populations.
Dental Reimbursement. Assists accredited dental schools and postdoctoral dental programs with uncompensated costs incurred in providing oral health treatment to HIV-positive persons.
AIDS Education and Training Centers (AETCs). This is a network of 15 regional centers that conduct targeted, multidisciplinary education and training for health care providers.

Services for Women and Children
Medical Evaluation and Clinical Treatment. Ensures all grantees comply with guidelines in terms of treatment.
AIDS Drug Assistance
Outpatient Substance Abuse Treatment Services. Collaborates with SAMHSA to meet the needs of the substance-abusing population.
Outpatient Mental Services. Addresses the issue of domestic violence as a deterrent, challenge, and barrier to care.
Oral Health Services
Referrals for Specialized Medical Care
Counseling and Testing
Support services. Addresses barriers to primary outpatient care: child care, transportation, emergency housing assistance, case management, translation services, client advocacy, and outreach. We need to provide more family care centers to address the needs not only of the women but of their spouses and children because women tend to put their own needs last. Case management needs to address of lack of education, geographic isolation, and emotional isolation.

Targeted Services to Reduce Perinatal HIV Transmission
- **Perinatal transmission targeted by all of the Ryan White CARE Act titles**
- **Outreach and education to women of childbearing age**
- **HIV counseling and testing**
- **Comprehensive clinical care for pregnant and postpartum women and their infants**
- **Provider education**
- **Follow-up primary care services for women and children**

The Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission (WIN) Program/Title IV Perinatal Initiative

This program provides activities to encourage women to learn about their HIV status and to provide them with a continuum of comprehensive care, from street outreach to long-term care. Needs that were identified include
- **Transportation**
- **Effective strategies to maintain pregnant women in care**
- **Co-location services**
- **Counseling**

- **Adequate prenatal care for underserved populations**
- **Outreach to substance-abusing and incarcerated women**
- **Adolescents in juvenile services**
- **Mental health**
- **Domestic violence**

WINS Lessons Learned

- **Women do accept testing, particularly during pregnancy.**
- **Voluntary HIV testing significantly decreases transmission.**
- **Late or no prenatal care remains a barrier to further reduction.**
- **Access local providers and consumers' needs to increase voluntary HIV testing.**
- **HIV education begins with outreach in nontraditional settings.**
- **Link testing to comprehensive systems of care and involve patients in care and decision making.**

Remember:
Women tend to place their own needs last, after they meet the needs of their children and family.

Women do not care how much you know until they know how much you care.

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Substance Abuse and Mental Health Services Administration (SAMHSA) —Lucy Perez

$7.5 million is devoted to outreach for substance abuse and HIV treatment services.
The Center for Substance Abuse Prevention (CSAP) receives $13.5 million for combination substance abuse prevention integrated with HIV prevention services. It is limited to communities of color.

Risk Factors for Drug Abuse

Abuse. Adolescent females who are coerced into sexual acts are especially at risk for engaging in risky sexual practices later in life. Approximately 70% of women in drug-abuse treatment reported histories of physical and sexual abuse with victimization beginning before 11 years of age and occurring repeatedly. In one clinic, 50% of HIV children were victims of incest; 32% of women who became pregnant before the age of 18 had a history of sexual assault.
Alcohol. Alcohol users and illicit drug users are intricately connected, which means if one is at risk for drinking, one is at risk for HIV disease. Violence, drinking, and HIV disease are also interconnected. It is particularly crucial that we get our message to adolescents. If we can prevent the first drink from age 15 to 19, we have a 30% probability of reducing the use of cocaine in a lifetime.
Stress. Women suffering from posttraumatic stress disorder are 17 times more likely to have a major drug-abuse problem.
Smoking. Cigarette smoking is a significant predictor of women in the progression from legal drug use to illicit drug use. Women may begin or maintain cocaine use to develop more intimate relationships.
Race/ethnicity. Racial and ethnic issues as they relate to HIV, perinatal services, substance abuse treatment are all interconnected, regardless how our agencies separate them. We're talking about the same people and the same issues.
Risky sexual behavior. Sexually transmitted diseases (STDs) have become a pediatric problem. Perinatal HIV disease cannot be discussed without including adolescent population and STDs. A survey from the Bronx showed that 41% of females and 33% of males acquired a new STD after diagnosis of HIV. This implies not only the risk of HIV but the probability of pregnancy.
Racial and ethnic disparities. The CSAP website, Making the Connection, at www.health.org/sa-hiv), makes the connection around racial and ethnic disparities as they relate to substance abuse and HIV. African Americans may be at greater risk for HIV disease because of incarceration. So perinatal HIV programs need to focus on incarceration, both adult and juvenile. The number of minority youth held in detention centers increased 79% from 1983 to 1991, while the number of white youth increased by 8%. There is a marked increase in women of color over the age of 50 with HIV disease.
Incarceration. Incarceration increases HIV risk because of more juveniles in detention centers, more people in jail, higher HIV seroprevalence rates in jail.

Indicators

Ignorance, not prejudice, may result in disproportionate health care. Health care providers need to see the socioeconomic and political indicators for why people are disproportionately affected by HIV disease. HIV risk and substance abuse risk come from the same populations. Five indicators of substance-abuse risk include:

- **Low family income**
- **Single-parent homes**
- **Women-headed homes**
- **High population density**
- **Education below 8th grade**

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Correctional Facilities —Kleanthe Caruso, National Commission on Correctional Health Care

I have been associated with correctional facilities for 16 years and have been in health care for over 25 years. I'm a registered nurse and have been responsible for the state of Texas health care delivery system for the state Department of Corrections. I am also the Chairman of the Board of the National Commission on Correctional Health Care.

Correctional facilities are really a mirror of the community. The people that come to the facilities have behaviors that put them at risk for serious health problems. Every state has a variety of correctional facilities—local, county, state, and federal.

Of all the prisons in the United States, about 450 are accredited by the National Commission on Correctional Health Care. Some of the standards apply to perinatal HIV elimination.

- **Continuity of care from admission into prison to discharge into the community is an important standard.**
- **Special needs offenders have been identified as those people who have infectious diseases and women who are pregnant. Special needs treatment plans are written for these persons. Because correctional facilities have limited resources, are in remote locations, and have limited providers, they have taken advantage of community services, departments of health, and indigent care hospitals to provide for special populations.**

What is the number of women in prison?

As of December 31, 1998, there were over 1,300,000 prisoners in federal and state jurisdictions. The number of incarcerated women under the jurisdiction of state and federal authorities increased about 6.5% during 1998 (79,268 to over 84,000), outpacing the rise in the number of men. These numbers do not include those in juvenile facilities.

What is the prevalence of HIV in correctional facilities?

Inmates have a higher rate of infectious disease than that of the general population. At year-end 1996, the rate of confirmed AIDS in state and federal prisons was 6 times higher than that of the total U.S. population. About 54 in 10,000 inmates had AIDS compared with 9 in 10,000 in the general population. In local jails as of 1996, of 31,972 females, 2.4% were HIV-positive compared with 2.1% of males. In state prisons, the number of females was over 55,800, with HIV prevalence at 3.4% compared with males at 2.2%. In the federal system, the prevalence among males and females was about the same.

New York has about a third of all the HIV-positive inmates in the United States, followed by Florida, Texas, and California. HIV prevalence is higher in females than males, and in black and Hispanic inmates.

What is the medical care system in correctional facilities?

Despite the above data, few correctional systems have implemented comprehensive HIV prevention programs. Most settings provide HIV antibody testing, but only seven states provide mandatory testing. Methods vary among states. Few have mandatory or routine pregnancy testing. Once a women is identified as pregnant, she is provided medical examinations, advice on activity and safety, and nutritional guidance and counseling.

Pregnant women released before delivery are handled by case management programs in prisons. Case managers may give the woman a booklet with the names of the closest providers, pharmacy numbers, local resources; they may set up hospital appointments for the women. Most offenders come from big cities, so resources could be concentrated in selected areas.

Is HIV care available in correctional facilities?

Most correctional facilities do provide treatment and medication for HIV-positive offenders. However, the programs and therapies vary among facilities, which depend on contract or community resources to keep them up to date. Most facilities are located in remote areas of the state, without much access to continuing education for their providers. More states have recently turned to contracting with outside providers or using telemedicine technologies to provide these services.

When an offender is on HIV treatment, the attitude of the health provider influences the behavior of the offender. Providers must understand the treatment climate when talking about compliance. Medications are generally not dispensed to inmates as they would be to someone in the community. Inmates may need to walk to a dispensary several times a day to obtain medication; this need underscores the importance of counseling and stressing the importance of adherence. Lack of adherence may contribute to resistant strains in these people who will eventually return to the community.

Is HIV care linked with community agencies?

Once a pregnant inmate is identified, she is referred to a community hospital, indigent care facility, or an individual health care provider. This is the first opportunity for community linkage with pregnant HIV-infected offenders. Because the female population is usually much smaller than the male population, these linkages are usually limited to one community site; this gives the community another opportunity to link with correctional facilities because they are not having to span the entire state.

Because many communities do not have a lot of sympathy for delivery of health care in correctional facilities, the federal government got involved and said it was a Constitutional right. Limited dollars go to prisons, jails, and detention facilities, and not all of it goes to health care.

What are the policies on compassionate release?

Policies for the early and compassionate release of inmates with terminal illnesses, including end-stage AIDS, are common, but few inmates are actually released.

What are the issues with relation to baby placement and baby care?

Most correctional facilities give pregnant women options on baby placement; e.g., whether the baby will go to the family, significant other, foster care, adoption. The decision is communicated to the hospital where the woman delivers. HIV-infected pregnant women need more consideration as to where the baby will go because of the needs of the infant for medication, laboratory work, and whether the infant's caretakers are willing to do this and whether the resources are available in the community.

For the management of HIV-infected pregnant woman, the key points are

- **Identification and referral to appropriate (infectious disease and obstretrics) service**
- **Evaluation of the woman (Previously on medication? Compliant? Willing to start treatment? Baby placement? Continuity of care?)**

The burden is to link up with these women before they are released into the community and ensure a smooth transition once they are released from the correctional institution.

Because incarcerated women are not eligible for Medicaid, there is a lag time between release and eligibility. Most HIV-infected offenders are given a short-term supply of medication before leaving the facility. Every state handles case management differently in terms of connecting with communities. Texas has a federally funded program with an 800 number that HIV-infected women can call to get the name of a participating pharmacy for a free supply of medication. Last year, only 40 out of 100 eligible persons made the effort to place the call, emphasizing the need for community follow-up.

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Health Care Financing Administration (HCFA) Programs and Policies —Michael McDaniel, HCFA

I'm here to answer any questions that you may have about the Medicaid program, because I work not just in HIV/AIDS but in several different areas in the Medicaid program in the Atlanta regional office.

HCFA Maternal HIV Consumer Information Project (MHIV-CIP)

Background

- **Medicaid is the largest single payer of direct services to persons living with AIDS.**
- **In the late 1980s, Medicaid began expanding eligibility income levels for pregnant women, working with each state individually to expand eligibility, coverage, and services. Eligibility ranged from 133% to 185% of federal poverty level.**
- **In 1994-5, the results of AIDS Clinical Trials Group (ACTG) 076, HCFA encouraged states to get more involved in getting information out about HIV counseling, testing, and treatment.**
- **HCFA's goal is to improve health outcomes and reduce morbidity and preventable deaths through education.**

What is MHIV-CIP?

- **It is a collaborative effort of HCFA and our state and community partners**
- **Focuses on the development and distribution of free informational materials aimed at alerting women of childbearing age to the benefits of HIV testing, counseling, and treatment, and potential eligibility for Medicaid.**
- **An initial pilot was run in 1995-6 in four states (RI, DE, 3 counties in NJ, 5 counties in FL).**
- **States design their own programs.**
- **It is expanding to 24 sites (an additional 16 states have CIPs, which use materials other than HCFA's).**
- **HCFA's 1997 National Performance Review goal on health promotion is to have 100% of states participating by the end of 2000.**
- **Materials include postcards and posters in 14 languages (English, Spanish, Bosnian, Chinese, Vietnamese, Japanese, French, Russian, Korean, Haitian Creole, Yupik, Hmong, Khmer, Portuguese) and videos in English and Spanish. New versions of the video are currently in production.**
- **Additional HCFA activities**
  - **Promote provider education.**
  - **Provide technical assistance to states to establish/maintain state-specific projects.**
  - **Maintain HCFA website (www.hcfa.gov/hiv/default.htm)**
  - **Share best practices in consumer education and public/private partnerships.**

- **Support (along with other Human Health Services agencies) the AIDS Treatment Information Service (ATIS).**

Primary Messages

- **HIV counseling and testing are important to women of childbearing age.**
- **Current drug regimens may significantly reduce transmission.**
- **Many pregnant women are eligible for Medicaid and other state/federal programs.**
- **Medicaid programs pay for HIV counseling, testing, drug regimens, and prophylaxis.**
- **Discussion of testing and reduction of HIV transmission is an integral part of prenatal care.**

Special services. States have the option of providing targeted case management. A lot of states target either pregnant women or people who are HIV-positive. Also, freedom-of-choice waivers (Medicaid waivers) can be used, which enables women to be directed to a specialist provider who will track them and provide comprehensive care.

Materials Available **(Contact regional HCFA HIV/AIDS coordinator. Specify language for materials)**

G **Posters**
G **Postcards**
G **Videotapes**

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Closing Remarks —Helene Gayle, Director NCHSTP, CDC

I want to thank all of you for coming to this meeting. I also want to thank all of our federal partners—HRSA, NIH, SAMHSA, HCFA—and of course, Janet, Martha, and the others who have worked so hard to pull all of this together.

This meeting is important to me. I am a pediatrician and started my career in HIV, at a time when all we could do about pediatric HIV was to study it. We have truly evolved from providing better and better therapies for children who have HIV and seeing children who were born with HIV live into adolescence, to a period where now we can make HIV in children an almost totally preventable disease.

Eliminating pediatric HIV as a major public health problem in this nation is one of our Center's highest priorities. We believe there is no reason, considering all that we know and all that we can do, for us not to do everything possible to make perinatal HIV transmission an extremely rare event in this country.

It is extremely gratifying for us to be able to merge our science and our prevention programs. I want to recognize David Holtgrave and Rob Janssen for their leadership in bringing our two HIV divisions—one of which is surveillance and epidemiology, and the other primarily prevention programs—together to collaborate on this very important issue.

We all know that preventing HIV in children is part of the broader goal of reducing HIV transmission to women. So although I hope we continue to focus on this important issue of perinatal transmission, we should also keep in mind the broader issues of continuing to prevent the spread of HIV infection in women, as well as the related issues such as substance abuse and other sexually transmitted diseases. The integration models that this program will necessitate are therefore very important as we look beyond perinatal transmission.

This project and the resources for it came out of part of the Ryan White language that also led to the Secretary of Health and Human Services having to determine whether or not testing for HIV and implementation of the perinatal guidelines should actually become routine practice in this country. And although we have not reached the point where every pregnant women is tested, by expanding the implementation of the Public Health Service guidelines we have made tremendous progress in reducing mother-to-child transmission.

I would be remiss in talking about perinatal transmission of HIV in this country if I did not also highlight the important role that the United States has played in the global efforts to prevent perinatal transmission. Today, 90% of children who are born with HIV live in developing countries, and the greatest burden is in Africa. We have learned a lot from our international efforts in countries such as Zaire, Côte,d'Ivoire, and Thailand. Many people in this room have been involved in international work. As we continue to find solutions here in this country, I hope we will continue to keep in perspective the global epidemic and to think about how we can

contribute to that fight as well. As we have learned a lot from our work in developing countries, we have an obligation to give back and to keep that broader issue in mind.

Clearly, preventing mother-to-child HIV transmission is also important because of the very important goal that the President, the Surgeon General, CDC, and everyone has made of eliminating health disparities in this country. This is an issue of racial and ethnic disparities in health. Hopefully, we can use perinatal HIV prevention as a model of how to tailor interventions for specific communities, particularly as we look at this very critical issue of eliminating disparities.

Finally, while perinatal transmission, relatively speaking, contributes a small amount to the epidemic, I think that the work we do here for this very important population will not only contribute to our efforts of reducing the spread of HIV overall, but it will also help to develop models that will be useful way beyond this issue. The work that you are doing in getting high-risk women into perinatal care is going to have a positive effect on infant health in general. If we can do a better job of developing this model for women who have been out of the reach of our care system, who have not accessed care, who come late to prenatal care, who do not get the quality services that they need, who are not integrated into other treatment services that they may need—mental health, substance abuse, and others—if we can use this as a model to develop some of these other systems and put these systems into place, we will have made an impact way beyond perinatal transmission. We will have made a major impact in reducing infant mortality in this country, reducing low birthweight babies, and many other things that we still struggle with in this country.

I want to thank all of you for attending this meeting and for all of the work that you are going to do in the days and months ahead. I hope that CDC can continue to be a resource to you, to be helpful to you, and to be a true partner to you in this effort. Thank you so much.

Workshops (A–H)

January 11–12, 2000

Special thanks are extended to the workshop rapporteurs—Louise Rice, Justin Ray, Cheryl Jablonski, Dianne Gaston, Roxanne Barrow, Bonnie Maldonado, Diane Abatemarco, and Roland Jimenez—for providing the workshop summaries.

Workshop A: Prenatal Care Issues— Ken Dominguez, chair

Goal: To improve access among high-risk women via already existing prenatal care services and to ensure that HIV perinatal prevention services are incorporated into prenatal care

Objectives: Strategies for Interchange Between States

- Discuss gaps in prenatal care for HIV-infected women and among women at highest risk for HIV infection
- Discuss critical elements in current prenatal care protocols as they relate to perinatal HIV transmission prevention
- Discuss ways of improving access to prenatal care among high-risk women
- Discuss ways to incorporate HIV counseling and testing services into prenatal care
- Discuss ways to coordinate prenatal care services and HIV-related treatment services

The Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission (WIN) Initiative, Health Resources and Services Administration (HRSA) — Lydia E. Soto-Torres, HRSA

The Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission (WIN) Program

This programs provides activities to encourage women to learn about their HIV status and to provide them with a continuum of comprehensive care, from street outreach to long-term care. Needs that were identified include

- Transportation
- Effective strategies to maintain pregnant women in care
- Co-location services
- Counseling
- Adequate prenatal care for underserved populations
- Outreach to substance-abusing and incarcerated women
- Adolescents in juvenile services
- Mental health
- Domestic violence

WINS Lessons Learned

- Women do accept testing, particularly during pregnancy.
- Voluntary HIV testing significantly decreases transmission.
- Late or no prenatal care remains a barrier to further reduction.
- Access local providers and consumers' needs to increase voluntary HIV testing.
- HIV education begins with outreach in nontraditional settings.

- Link testing to comprehensive systems of care, and involve patients in care and decision making.

HIV Prevention and Education in a Managed Care Setting —Enid Eck, Kaiser Permanente

Drivers of Prevention

- Improved care management (quality)
- Eliminating gaps in services
- Assuring the right person for the job
- Promotes healthy outcomes.
- Compassion, creativity, and optimism
- Improved patient satisfaction
- Physical
- Emotional
- Spiritual
- Psychological
- Improved cost-efficiency
- Minimized duplication
- Direct access via multiple venues
- Oriented toward effective outcome

Assuring and Monitoring Care

- Process indicators
- Assessing that linkages are in place
- Documentation achievable
- Outcome indicators
- Disease-related outcomes
- Health outcomes
- Quality vs. quantity of life measures

Special Population Example

- Perinatal risk assessment and reduction
- Standardized treatment protocols
- Multidisciplinary Care Path across care continuum

Primary Prevention

- Is population-based.
- Incorporates best learning theories.
- Modifies modalities as needs change.
- Captures learning readiness.

Focus on Innovation

- Identify the "real" needs of the patient.
- Creatively structure service delivery; provide one-stop shopping, transportation.
- Verify the need is effectively addressed; go back and assess effectiveness.
- Remember: Numbers aren't everything; put a face to the numbers.

The Targets of Prevention

- Primary prevention
- Secondary prevention
- Tertiary prevention
- Promoting the health of our communities

Community Action for Prenatal Care (CAPC) Initiative —Roberta Glaros, New York State Department of Health

Target Area: Selected ZIP codes of The Bronx, Brooklyn, Manhattan, and Buffalo

Identified program components through

- Focus groups
- Providers (63 front-line providers)
- Consumers (46 high-risk women)
- ZIP code targeting strategy (identification of intersection of areas with elevated HIV and areas with high rates of little or no prenatal care)

Essential Components for Helping High-risk Women Stay in Prenatal Care

- Establish and maintain trust. Establish ongoing relationships between women and their providers (using case management, peer outreach, consumer involvement, providing transportation and easy access to services).
- Coordinate/mobilize existing services [HIV, substance abuse, maternal child health (MCH)].

- Provide thorough training of
- Health providers
- Outreach workers
- Supervisors
- Promote a prenatal care message, not just HIV care.

The CAPC Model

- Engaging high-risk pregnant women in care (through social marketing, outreach, development of a recruitment network consisting of community agencies serving high-risk women)
- Intake (through accessible sites, home visits, core services, short-term case management)
- Comprehensive referral system (for all needed services)

CAPC Evaluation

- Outcomes by target area: HIV transmission rate, prenatal care for HIV-infected women, birthweights
- Process: Measured by recruitment method, demographics, referrals to various services, completed referrals

CAPC Unique Features

- Incorporates information from consumers and previous efforts.
- Is a comprehensive model.
- Focuses on the woman.
- Combines expertise of HIV, MCH, and substance abuse programs.

Reaching Pregnant Women through the Media: The Case of Louisiana—Daphne LeSage, Louisiana Department of Health and Hospitals

Perinatal Initiative 2000 has four components:

- Rapid testing in statewide public hospital emergency rooms
- Perinatal registry
- Case management with peer counselors
- Media campaign—promotes HIV awareness, Know Your Status
    - Multiple modes of communication (e.g., pizza box containing pocket cards, placards, brochures, all with multiple messages)
    - Disclosure—Although many women know their status, they may not want to disclose it and shift the focus during delivery. We need to emphasize the importance of disclosing HIV status at or before delivery.
    - Focus should be on having a healthy baby rather than on HIV testing.

Workshop A: Summary

Continuing Gaps

- Transportation, child care
- Cultural competence (Need providers who speak same language as their clients—linguistically, socially and culturally.)
- Need for retesting, continuous risk assessment
- Domestic violence, past and present
- Provider's abilities to assess domestic violence situations
- Resource/service network
- Fear
- Child protective
- Welfare reform
- Immigration

- Effective referrals (user friendly)

Promising Models

- One-stop shopping
- Continuum of care and contact from street outreach through long-term care
- Specialized training (skills) at multiple levels (outreach workers, supervisors, providers trained separately)
- Community-based peer leaders, as essential members of the team
- Creative outreach strategies
- Social marketing
- Standardized protocols and documentation
- Integration of HIV counseling and testing and treatment services into overall plan for comprehensive prenatal care services and media campaigns about having a healthy baby

Workshop B: Prevention for Women Without Prenatal Care (Rapid HIV Testing) —Marc Bulterys, chair

Goal: To increase knowledge about voluntary rapid HIV testing in late pregnancy as a crucial opportunity for health care intervention for both mother and infant

Objectives:
- Provide an overview of the CDC-sponsored Mother Infant Rapid Intervention at Delivery (MIRIAD) project
- Discuss availability and performance characteristics of HIV rapid tests
- Assist states in extending the benefits of short-course antiretroviral therapy (ART) to pregnant women with little or no prenatal care in high HIV-prevalence areas
- Discuss potential implementation strategies and the informed consent process
- Discuss recently established and planned prevention programs in some areas
- Invite states to share their expertise with rapid HIV testing

Overview of MIRIAD —Marc Bulterys, CDC

Most HIV-positive women deliver their babies within a hospital setting. The results of the MIRIAD project will lead to best-practice recommendations for care of late-presenting women.

Objectives
- To evaluate innovative approaches to counseling and testing for women with unknown HIV status presenting at the time of delivery
- To assess feasibility of obtaining informed consent during labor or soon after
- To describe reasons for lack of care
- To assess delivery of ART to late presenters (new Public Health Service guidelines being reviewed)
- To evaluate neonatal therapy adherence and evaluate postnatal care for HIV-infected women

The MIRIAD Project
- Limited to institutions with relatively high ($1%) HIV seroprevalence in Atlanta, Chicago, Miami, New Orleans, NYC.
- Will link collaboratively with Pediatric Aids Clinical Trials Group (PACTG) protocols for the next four years.
- First year protocol development and piloting; expansion to other hospitals in geographic area during subsequent years.
- Will evaluate rapid HIV test algorithms.

- Will collect infant blood (at birth, 2 wk, 4 wk, 2 mo, 4 mo, 6 mo) for virologic testing, and will conduct virologic/immunologic substudies to clarify mechanism of action of neonatal postexposure prophylaxis and to characterize breakthrough infections.
- Proposes to assess pre-existing HIV ART resistance in a population of drug-naive women who access care late in pregnancy.

Behavioral Research Issues
- Find barriers to or reasons for lack of prenatal care.
- Measure perceived social support and psychosocial assets.
- Assess feasibility of informed consent during labor and linkage to care after delivery.
- Evaluate predictors of foster care referral and impact on ART adherence.

Conclusions
- Intrapartum rapid HIV testing for women without prenatal care offers a crucial opportunity for health care intervention for both mother and infant.
- Such policy appears cost-effective, especially in hospitals with maternal HIV seroprevalence above 0.7% (Am J Obstet Gynecol 1999;l181:1062–71).
- How best to provide rapid HIV testing and peripartum treatment options needs systematic research.

Update on Rapid Testing — Bernard Branson, CDC

Types of Tests

Flow-through devices
- Single Use Diagnostic System for HIV-1 (SUDS, Murex Corporation), the only test approved by the Food and Drug Administration (FDA) for use in the United States
  - Advantage: Concentrates antigen
  - Disadvantages: Multiple steps are required. Need certified laboratory to perform. Fastest turnaround is one hour.
- Multispot 1-2
- RTD
- Quix

Agglutination tests (often used in Africa). Require high degree of skill by reader to get high specificity/sensitivity.
- Recombigen
- Serodia
- Capillus
- Simpli-Red

Dipstick or capillary flow tests. Antigen will turn color. Has a control line for comparison. Is quick and easy, but may not be as sensitive as other tests.
- Determine
- SeroStrip

- HemaStrip
- UniGold

CDC's rapid test evaluation, using 400 stored serum specimens

Test	Sensitivity (%)	Specificity (%)
Determine	100	98
HemaStrip	98.5	99.5
Quix	100	97.5
UniGold	99	96
SUDS	97.9	94.5
HIV 1-2 EIA	–	95.1

New data have come in from Los Angeles County. A laboratory examined 800 prospective samples to evaluate various rapid tests on fresh specimens. Comparing three types of blood samples—fingerstick, whole blood, plasma—the plasma produced the highest sensitivity and specificity.

FDA Considerations

Investigational Device Exemption (IDE) allows for shipping products not yet approved to study sites.

Expanded access ("treatment IDE") is being explored by CDC, enabling use of a product before FDA approval if it is deemed a public health necessity.

The Louisiana Experience in Charity Hospital —Robert Maupin, Louisiana State University School of Medicine

Testing Protocol: Used Murex SUDS assay concurrent with conventional HIV antibody tests on all late-presenting obstetric patients with undocumented status who consented to HIV testing.

Objectives

- To examine performance of HIV rapid testing methods in an obstetric population
- To evaluate ability to administer intrapartum and neonatal zidovudine (ZDV) prophylaxis to women in labor
- To examine patterns of entry into primary care for HIV-infected childbearing women identified by rapid tests

Findings (over 11 months)

- 479 women were screened by SUDS. 15/18 positive SUDS tests were confirmed. Seroprevalence was approximately 3.1%, test sensitivity 100%, specificity 99.4%, positive predicting value (PPV) 83%.
- In the first seven months of the obstetric rapid test program, 20% of HIV-positive women delivering were diagnosed by rapid testing. Intrapartum ZDV was given to 63% at delivery. 20% of those women used on-site primary care services.
- 100% of neonates received ZDV prophylaxis, and all newborns entered HIV clinic follow-up after discharge. HIV infection status was determined on seven of eight newborns. One of seven infants was infected (born to a mother who did not receive intrapartum ZDV).

Costs (over 11 months)
SUDS = $27.50
Positive control, negative control, patient sample = $7.50 X 3
Lab fee = $5.00
Total for 11 months = $13,172

Conclusion
In a medical facility with organized support and collaboration, where start-up and training costs are minimized, the project was successful. The SUDS assay performed adequately in a high-seroprevalence (>3%) obstetric population. The benefit is that intrapartum rapid HIV testing allows for administration of intrapartum and neonatal antiretroviral prophylaxis in late-presenting childbearing women without prenatal care.

Discussion
Q: Have providers voiced concerns about using a non-FDA approved test?
A: First, rapid tests are confirmed using standard enzyme immunoassay (EIA) and Western blot techniques; second, several states have time or minimum sample numbers. These non–FDA-approved assays have been tested extensively in international settings, and their performance is generally superior to that of SUDS. Providers have been concerned about the high rate of false-positive results with SUDS.

Q: In New Orleans, how do you deal with the ethics of informed consent?
A: One woman whose test was false-positive understood the information. Counseling sessions covered results and testing false-positive or false-negative. One woman who tested false-positive was tested for occupational exposure (early prenatal HIV testing was negative) and had to validate with further tests. Informed consent covers the principles of testing (including the potential for false-positive test results) and options for maternal/newborn prophylaxis.

Q: What is the extent of post-test counseling?
A: It has been built into MIRIAD as protocol and is in the form of a two-tier post-delivery discussion.

Q: Is there a policy on cesarian sections?

A: That is currently a separate issue from rapid testing. In New Orleans, one-half of all women tested already had membrane rupture; thus, an elective cesarian-section is often no longer an option.

Q: Is ART started on the basis of rapid test results?
A: Yes, for neonatal prophylaxis. This is discontinued immediately if confirmatory HIV testing comes back negative. The New Orleans experience tells us, however, that many mothers found to be HIV-infected during labor do not continue on ART for their own health.

Q: In Massachusetts, data suggest lack of prenatal care is not a factor in HIV-positive births. To prevent stigma, where do you draw the line as far as who is tested?
A: MIRIAD strives for broad coverage among women who present late in pregnancy with undocumented HIV status. Thus, at hospitals participating in MIRIAD, all women without documented HIV status will be offered intrapartum rapid HIV testing.

Q: How do you link follow-up with primary care?
A: In New Orleans, there is a collaborative relationship between the medical center and an onsite primary care center. Referrals are made prior to discharge. In the MIRIAD project, we will make extensive efforts to link HIV-infected women into primary care and ART for their own health.

Q: What should the objective be for rural/outlying areas?
A: Rely on contacting regional centers for help in expertise areas. Talk to infection control professionals. Seek community members to give support and consultation. HIV prevalence in many rural areas may not justify a MIRIAD-type intervention at labor and deliver; however, voluntary confidential counseling and testing during pregnancy should be widely available everywhere.

Workshop C: State Laws, Regulations, and Policies Affecting Prevention of Perinatal HIV Transmission — Kathy Rauch, chair

Goal: To inform and discuss ways in which policy at the national, state, and local levels can impact prevention of perinatal HIV transmission

Objectives

- Discuss ways in which state laws, regulations, and policies can impact perinatal HIV transmission
- Discuss issues and lessons learned from the recent Connecticut experience with a new state law for perinatal HIV screening
- Discuss potential Medicaid and other policy interventions to prevent perinatal HIV

Continuum of Interventions

Law	o **Regulation**	o **Policy**
Least changeable	More flexible	Most changeable and flexible
May not be what public health wants		More predictable by public health
Highly enforceable	Somewhat enforceable	Not very enforceable. (To improve enforceability, approach licensing boards, put policy language in contracts.)

Legal and Ethical Analysis — Zita Lazzarini, University of Connecticut Health Center (UCHC)

UCHC analyzed legal issues and summarized a national survey of state laws.

Purpose

- Compare state laws and policies with 1995 Public Health Service (PHS) recommendations.
- Analyze legal and ethical issues.
- Identify barriers to 1998 Institute of Medicine (IOM) recommendations.

Method. Surveyed state epidemiologists in all states and territories.

Response. 49 states and Guam responded.

Conclusions

- States moved quickly to implement PHS guidelines (47 states had a regulation, law, or policy).
- Majority have policies (45); fewer have laws/regulations (27).
- Most efforts rely on education, counseling, and consensual testing.
- Most had policies/guidelines or laws to cover testing pregnant women (45 policies; 25 laws).
- Some had policies/guidelines or laws to cover treatment of pregnant women (35 had policies; 7 had laws/regulations).
- Fewer states have laws or policies regarding newborns (26).
- Few states incorporate mandatory or coercive actions into testing provisions (0 mandate testing pregnant women; 3 mandate testing newborns).
- Over half the states have criminal sanctions for knowing or intentional exposure (29); no state has applied laws to perinatal transmission.
- A few states exempt pregnancy from the modes of exposure for purpose of knowing exposure laws.
- Washington Department of Health determined that the law would not apply to perinatal transmission unless the mother intended to harm the child.
- The Institute of Medicine (IOM) recommends "universal HIV testing, with patient notification, as a routine component of prenatal care."
- Only 5 states currently have routine "opt out" provisions that most closely reflect the IOM recommendations.
- Changes in state laws would have to occur to implement IOM recommendations that could conflict with the states' own pretest counseling and informed consent laws.
- Potential barriers include: 40 states require voluntary testing based on informed consent (35 by law; 5 by policy).
- 8 states have "opt in" provisions for testing (very close to informed consent requirement).
- 21 states specifically mandate pretest counseling by law.

Discussion

- Largely voluntary approaches have cut new pediatric HIV cases by 66%.
- Voluntary HIV testing is the current norm.
- Although there may be public health justification, coercive policies can deter testing and reduce trust.
- Detailing what providers must discuss in the language of the law can intimidate providers.
- Don't let policy changes get ahead of scientific evidence.
- States hesitate to go back to their legislatures when the current law has been successful.
- Revised legislation could be awkward to implement.
- Some fear that legislatures may take the opportunity to open up broader discussion of mandatory testing, at least for certain populations (e.g., healthcare workers exposed by needlestick), leading to incremental changes.

Connecticut Experience—Richard Melchreit, State of Connecticut

- In 1992 (predating Pediatric AIDS Clinical Trials Group 076), Connecticut passed a law that simply stated that obstetricians must offer the test to pregnant women.
- In the 1999 session, the Connecticut legislature began a process to revise the law, because some women were being missed as demonstrated by anecdote and evaluation data.
- The session ended in early June without action on the issue. During a special session later that month, the new law was passed as part of an omnibus health and human services bill.

Details of New Law

- Providers must counsel and offer HIV testing to pregnant women at enrollment for prenatal care and during the third trimester.
- If the woman is not tested prior to delivery, she is to be tested at delivery, unless she refuses and signs a declination form.
- If the woman does not get tested at delivery, then the baby must be tested except in the case of religious exemptions.
- When testing of the newborn occurs, the mother must be informed of results within 48 hours of delivery or before leaving the hospital, whichever comes first.
- The Connecticut Hospital Association petitioned federal court for a temporary restraining order to prevent the law from going into effect on October 1, 1999. That petition was denied, so the law is in effect. However, a lawsuit is going forward. The plaintiff in the lawsuit is arguing that the testing called for by the law is an unconstitutional search and seizure.

Issues

- Watch what laws other states pass because legislators talk to each other.
- Simplicity in legislative language is helpful to all affected.
- Stakeholders in any new law will be seeking information. Organizations in positions to provide technical assistance should be prepared to be proactive.
- Don't take assertions at face value without the backup of reliable data.
- Reauthorization of the Ryan White CARE coming up this year may be an appropriate vehicle for continued support of perinatal HIV prevention.

Medicaid and Other Policy Interventions — Kathy Rauch, Centers for Disease Control and Prevention

Public health officials are more likely than anyone else to convince Medicaid to adopt policies relating to HIV prevention.

Extent of Medicaid Coverage

- 38% of U.S. births during 1996 were covered by Medicaid.
- For women 15 to 44 years of age, who delivered a live infant between 1991 and 1995, 62.0% of non-Hispanic black women, 56.3% of Hispanic women, and 23.0% of non-Hispanic white women were covered by Medicaid for their most recent delivery.

- Medicaid is the largest source of HIV/AIDS financing in the United States, with estimates of $3.9 billion of HIV/AIDS expenditures; this is more than twice the $1.4 billion under the Ryan White CARE Act (RWCA).
- According to the Health Care Financing Administration (HCFA), Medicaid serves more than 50% of persons living with AIDS and up to 90% of all children with AIDS.

Encourage State Medicaid Agencies to

- Make perinatal HIV prevention a priority in their planning for both fee-for-service and managed care.
- Ensure HIV prevention and care services are in the capitation rate or paid through direct billing.
- Advise Medicaid providers of HIV prevention policies and available resources.
- Include specific language on HIV benefits and services in
    - Requests for Proposals (RFPs)
    - Managed care contracts (a place that policy can be given some "teeth")
    - Primary care case manager (PCCM) letters or contracts
- Include prenatal HIV testing performance measures in managed care contracts, especially in high-incidence areas and areas with low Health Plan Employer Data and Information Set (HEDIS) scores on prenatal care.
- Identify testing performance as a performance improvement project.
- Investigate performance in external quality reviews.
- Share performance results with public health.
- Have health plans work with public health to improve performance.
- Use financial incentives with health plans to achieve and maintain performance in testing pregnant women and delivery of prenatal care (could be withheld and then awarded if the plan achieves a stated level of performance, or could be a reward).
- Require or encourage health plans to
    - have clinical policies to facilitate universal HIV testing of pregnant women, and
    - collaborate with public health to establish effective clinical policies and to share educational programs.

Explore with the Medicaid Agency

- Requiring or encouraging participating hospitals to have
    - clinical policies to facilitate universal HIV testing of pregnant women; and
    - testing protocols, policies, and antiretroviral therapy available in labor and delivery units.
- Providing financial incentives to PCCM providers to test and counsel women of childbearing age in areas of high HIV prevalence
- Determining eligibility for incarcerated women prior to release, to ensure continuity of care

Workshop D: Effective Community Outreach Strategies for Perinatal HIV Prevention — Janet Cleveland, chair

Goal: To increase workshop participants' knowledge of effective and innovative outreach strategies for the prevention of HIV perinatal transmission

Objectives

- Provide an overview of the importance of providing outreach services as part of a comprehensive plan for preventing HIV perinatal transmission
- Identify innovative outreach strategies which clinicians and community-based organizations may utilize for preventing HIV perinatal transmission
- Identify and address challenges to providing effective outreach services
- Examine critical components of an outreach program from the consumer's perspective
- Share experiences of model programs

Responding to the Goals — Laura Riley, Massachusetts General Hospital

Models that work include state-of-the-art medical care, substance abuse and mental health counseling, childcare services, which are all enhanced by peer advocates for women at risk or HIV-positive women receiving care.

CDC data show that HIV diagnosis was made prior to delivery in 68% of women in 1993 compared with 81% in 1996. This improvement is not good enough. We need to reach more women with our prevention information and testing strategies so they can make informed decisions for their unborn children.

Peer Education/Advocacy Program

Examples of programs that aid in this effort:

A comprehensive prevention and risk reduction project in the African American communities in Georgia provides youth education, parenting education, and collaboration with other community-based organizations (CBOs).

Women Helping Women, a national organization, involves peer education within specific ethnic groups.

Community/Media Projects

Documentaries of women relating their personal experiences with HIV are very effective. Television soap operas that incorporate HIV/AIDS into the storyline also generate viewer interest (measured by calls to hotlines following airing of the programs).

Coalition of Black Churches in Boston. The impact of the clergy in the African American community is potentially profound. They may reach some women in a way that agencies cannot, given their ability to change social norms and facilitate discussions of sexuality.

Provider Education. Continuing education of doctors, nurses, physician assistants, and midwives is key. Continually update guidelines and gather information from multiple sources, including sources used by practitioners; e.g., American College of Obstetricians and Gynecologists (ACOG), American Association of Pediatrics (AAP), and CDC. Provider education must be relevant and practical within the context of a routine visit; e.g., must not take a lot of time.

Practitioners have several other things to discuss within a short office visit. Incorporate sexually transmitted disease (STD) and HIV prevention in routine clinical care. Talk about concerns for HIV with every patient. Redirect the notion of general obstetrician-gynecologist (ob-gyn) providing care for HIV-infected women, and support collaborations with appropriate expertise.

Key Message: Dispel the "at risk"concept; make HIV counseling and testing a routine part of obstetrical care, and make counseling guidelines practical for use within the context of a routine office visit.

Sisters Together and Reaching (STAR) — Debra Hickman

Rev. Hickman succeeded in responding to a challenge to reach 150 women. After initial contact, she noted these women often returned for second and third prenatal care visits. She reached these women in places they frequent; e.g., their homes. She met women who were not HIV-positive but were at risk, women who had no prenatal care, no insurance, felt unwanted and leery of the long waits for service or how they would be treated when they went for services.

In our service organizations, everyone involved must know how to reach out to each individual. For the pregnant women, it is challenging just to be able to show up for an appointment. We often don't know what it took for her just to get there.

Basic Suggestions for Outreach

- Be courteous.
- Make a good first impression.
- Consider other issues besides pregnancy that the woman may be dealing with. Social issues often determine the woman's compliance.
- Help each woman feel empowered; i.e., help her choose her next appointment.
- Explain treatment in lay terms.

- Pair women with persons with whom they can identify (peer counselors), persons who are suitable and sensitive to the job.
- Educate everyone (through in-home parties, communities, businesses).
- Offer incentives (baby showers). Collaborate with companies in giving in-home parties.
- Be aware that providers have limited time for outreach.
- Involve the front-line staff.
- Educate, educate, educate.

Key Message: It is possible to successfully contact hard-to-reach women, but you must go where they are and deal with them on their level, recognizing their concerns and needs.

AID Survival Project —Marcya Gullatte-Owens

This project is an organization that began in Georgia; it is known for its HIV Resource Center.

Ms. Gullatte-Owens shared a very personal story of coming from a middle-class background, being well-educated and informed on health issues, at low risk for HIV infection—until she discovered in 1994 that she was HIV-positive, pregnant, and had a dysplasia that could lead to cervical cancer if not treated. She spent the early days of her pregnancy dealing with "morning sickness" type symptoms. She stated she did not want to deal with the HIV. She said, "I chose to bottle it up and focus on the pregnancy and completing college."

During her second pregnancy, after much difficulty in finding a physician who could help her, Ms. Gullatte-Owens ultimately encountered doctors who understood her needs for HIV treatment and her pregnancy issues. Two doctors, an infectious disease specialist and an ob-gyn, worked together. They formed a team and a treatment plan, and Ms. Gullate-Owens delivered another healthy baby. The children are four years and nine months apart in age.

Ms. Gullatte-Owens' story shows the need for outreach and education efforts to be in place at all levels of the continuum of care so that women know and get the support they need to eliminate perinatal transmission of HIV. Women should not have to work as hard as she did to obtain accurate information and a support system to allay their fears and apprehensions. Women should not have to fight as hard as she did to find a provider who understands the special needs surrounding HIV infection in pregnancy. Ob-gyns and infectious disease specialists should work together. HIV-infected women should not be made to feel like criminals for becoming pregnant. Women should be educated about HIV prevention and treatment by their providers, and not vice versa, as in Ms. Gullatte-Owens' case.

"I learned that we must reach out to everyone along the continuum of care— from the patient to the provider to social agencies—to eliminate perinatal transmission. Outreach is ongoing."

Workshop E: Perinatal Training Models and Resources—

Jill Leslie, chair

Goal: To help improve the ability of providers to reach women of reproductive age and support these individuals in making decisions and behavior changes that will reduce their risk of acquiring or transmitting HIV

Objectives

- Identify and locate available educational resources regarding the prevention of mother and child transmission
- Identify at least two different training resources regarding HIV counseling and testing for women of reproductive age
- Identify at least one innovative method for targeting educational and counseling messages to women of reproductive age

Educational Resources

American College of Obstetricians and Gynecologists (ACOG)

Information Packet

· Joint American Academy of Pediatrics (AAP) and ACOG statement on counseling and testing
· Committee Opinion on cesarean deliveries (prevention of vertical HIV transmission)
· Patient education flyer, *HIV Testing in Pregnancy*
· Tear pad with patient education materials for examination room)
· Laminated fact sheet for physicians (for examination room)
· Order form for Video, *HIV and Pregnancy, What Every Woman Should Know*

Postgraduate courses (listed on website)

Academy of Medicine of New Jersey

- *AIDS Line* (newsletter)
- 609.275.1911

National Pediatric and Family HIV Resource Center (NPHRC)

Literature: (available in English and Spanish)

- Pocket card: *Guidelines for Use of HIV Antiretroviral Therapy in Pregnancy/Follow-up Care for Infants Born to Mothers with HIV Infection*
- *Reduction of Perinatal HIV Transmission: A Guide for Providers*
- *What Women Need to Know: The HIV Treatment Guidelines for Pregnant Women*

Web page

< For health and social service providers (www.pedhivaids.org)
< For families and caregivers (www.fxbcenter.org)

< For kids and teens (www.kidsconnect.org)

Centers for Disease Control and Prevention (CDC)

CDC offers Fundamentals of HIV Prevention Counseling to community-based organization (CBO) or health department staff members, and other trainers.

- Train-the-trainer model
- Four-day training
- Contact Theresa Moss (404.639.2918)

Training Resources

National Pediatric and Family HIV Resource Center (NPHRC)

Targeted training of health care providers

- Train-the-trainer (faculty training) model
- Support for trainers
- Outcome evaluation
- Contact www.pedhivaids.org

Centers for Disease Control and Prevention (CDC)

Fundamentals of HIV Prevention Counseling

- Train-the-trainer model
- Four-day training
- Contact Theresa Moss (404.639.2918)

Innovative Methods

· Peer education
· Special populations (women's correctional facilities, Inmate HIV Specialist Program)
· Roving seminars (Academy of Medicine of New Jersey, 609.275.1911), a pool of experts who give grand rounds or other types of presentations within New Jersey. Perinatal HIV Transmission is one lecture in this series.
· Physician aids—ACOG (patient education tear pad, physician reference sheet), California flip charts with patient information on one side and physician cues on the other

Other Issues

Training information should be appropriate for the audience, culture, literacy level, and language. The Health Care Financing Administration (HCFA) has free materials available in 14 languages; CBOs are another resource for multilingual materials. Job aids, brochures, etc., should be supplemented with face-to-face counseling.

Workshop F: Evaluation of Prevention Programs —Mary Glenn Fowler and Mary Lou Lindegren, chairs

Goal: To discuss with states the types of data that should be collected by states as part of monitoring and impact evaluation of the Perinatal HIV Prevention Program

Objectives

- Assist states in collecting data regarding the monitoring and impact of their programs on perinatal HIV prevention
- Discuss different Centers for Disease Control and Prevention (CDC) and state data collection instruments already available and share states' experiences using these instruments
- Discuss approaches to collection of data on specific targeted perinatal prevention programs
- Discuss how monitoring and impact tools can be used in an ongoing manner to improve program efficiency and outcomes

Guiding Principles of Evaluation — Mary Glenn Fowler, CDC

This workshop begins the process of sharing strategies and reviewing state approaches. CDC is creating an internal evaluation group with ongoing meetings. Input by states is important. A summary of evaluation tools and methods should be ready by midsummer.

Evaluation

- Should be conducted within the context of ongoing surveillance and data collection.
- Should use targeted programs that evaluate impact on women and children.
- Should use a standardized approach to data collection of key variables, not necessarily all survey instruments.

Strategies/Approaches/Resources

- Use of pediatric enhanced surveillance and other data sets available in states
- Targeted perinatal programs
- Summary progress reports (provided to CDC by grantees)
- Surveys to evaluate materials and educational packages developed by national organization partners

Summary of State Proposals —Abu Abdul-Quader, CDC

All grantees target some or all populations specified in Request for Proposal; i.e., women consumers, providers, public health agencies.

Targeted women include women who are in the general population, of childbearing age, pregnant, HIV-infected, substance abusers.

Intervention strategies targeting women include

- Outreach
- Social marketing
- Testing and referrals
- Prevention case management
- Enhanced case management
- Risk assessment

Health care provider interventions include

- Information dissemination
- Education
- Training workshops
- Lectures and seminars

Interventions targeting others—health department staff, staff at drug treatment facilities, and sexually transmitted disease (STD)/HIV surveillance staff— include

- Training and education
- Collection and analysis of data
- Review of medical record
- Cross-training of staff from Women, Infants, and Children (WIC), Maternal and Child Health (MCH), and drug treatment programs

In addition, other activities include collaboration with various agencies, building coalitions, establishing linkages with the community.

Epidemiologic Profiles and Datasets Already Available for Development and Assessment of Epi Profile — Mary Lou Lindegren, CDC

Enhanced Perinatal HIV Surveillance

Thirty-two states currently have named HIV reporting. Funding for enhanced perinatal surveillance is in 22 of those states with the highest seroprevalence. Enhanced perinatal surveillance is an expansion of Surveillance to Evaluate Perinatal Prevention (STEP), a surveillance project initially implemented in four states (NJ, SC, MI, LA) in 1996 and was instrumental in the recent Institute of Medicine (IOM) report findings.

- Enhanced ascertainment of mother-infant pairs: active case findings at pediatric sites and obstetric hospitals, matching of HIV/AIDS registry to birth registry, laboratory reporting, and women pregnant at the time of report
- Systematic ascertainment of data from multiple sources: maternal HIV clinic, prenatal, labor/delivery, newborn and pediatric records, standard case report form and supplemental data collection form, active follow-up of exposed infants every 6 months for infection status

- Collaboration with programs (HIV prevention, MCH, substance abuse)

States without HIV Surveillance

- Alternate methods to collect data on HIV-infected mothers and their newborns—facility-based collection of enhanced perinatal HIV surveillance data, with Institutional Review Board (IRB) approval at those facilities
- Standard case report form and supplemental data collected on HIV-infected mothers and exposed children at those selected facilities (prenatal care, HIV testing, ART)

Characterizing the Local Perinatal HIV Epidemic and the Impact of Prevention, Using HIV and All Available Sources of Surveillance Data

- Prenatal care
- General population [birth certificates, Pregnancy Risk Assessment Monitoring System (PRAMS)]
- HIV-infected women (enhanced perinatal HIV surveillance)
- HIV counseling and testing
- All pregnant women [birth certificates, PRAMS, audit of hospital prenatal records at Emerging Infections Program (EIP) sites]
- HIV-infected women (enhanced perinatal HIV surveillance)
- Use of antiretroviral therapy—ART, enhanced perinatal HIV surveillance, Survey of Childbearing Women (SCBW)
- Outcome of child (enhanced perinatal HIV surveillance)
- Other sources [Medicaid, Supplement to HIV/AIDS Surveillance (SHAS), HIV counseling and testing, Pediatric Spectrum of Disease (PSD)]

States are in different stages of data collection from some or all of these sources. New Jersey and New York City have enhanced perinatal HIV surveillance data already and other data sources as well, and those will be presented during this session.

Here is an example of Connecticut Surveillance Data.

- Pediatric HIV surveillance data, including perinatally exposed children
- Survey of prenatal providers
- Audit of provider medical records

State-specific Strategies. New Jersey and New York are “seasoned” sites; Florida demonstrates a more recent but successful surveillance/intervention.

New Jersey —Diane Abatemarco

- Resources/information are available to other sites especially PRODAS, SAS analysis programs, especially for merging registries.
- NJ program is a hybrid of surveillance and prevention with strong outcome evaluation component.
- Perinatal prevention is done by mobile outreach through local committees with a surveillance representative on these outreach committees.
- Tools
    - HIV/AIDS Reporting System (HARS)
    - Survey of Childbearing Women (SCBW) - Local funds to continue ZIP-code– based risk
    - Surveillance to Evaluate Perinatal Prevention (STEP) - Medical abstract survey to evaluate maternal-infant pairs 1994 to present. Looks for missed opportunities (otherwise known a enhanced perinatal HIV surveillance).
    - Birth certificate matching
    - Studies - SHAS or graduate student studies
    - New HIV counseling information module on birth certificate
    - Exploring laboratory database as potential use of provider change in testing patterns

Review of NJ Studies

- Knowledge, attitudes, beliefs, and intentions surrounding ZDV use—pregnant women, more knowledge relates to more adherence
- Diffusion of HIV counseling by NJ obstetricians/gynecologists
- Factors related to pregnant women ZDV use—algorithm of how to look at risk factors for ZDV use

Lessons Learned from STEP in NJ. Large number of women receive poor or no prenatal care. Next "step" for enhanced perinatal surveillance in NJ

- Combination therapy, adverse events, resistance
- Viral load (April 2000 law change to include reporting of viral load)
- Mode of delivery (elective cesarian section for HIV prevention)

New York State — Jim Tesoriero, Brian Gallagher

NY Task Force for the Prevention of Perinatal HIV Transmission Evaluation Workgroup Goals

- Increase prenatal care use to $95%.
- Increase rate of prenatal HIV testing to 90% in hospitals targeted for testing.
- Increase percentage of HIV-infected women and infants who receive full 076 antiretroviral therapy from 51% to 90%.
- Reduce perinatal HIV transmission in each target area from 12% to <5%.

Community Action for Prenatal Care (CAPC) Initiative

- Target areas are Bronx, Brooklyn, Manhattan, Buffalo. Focus on areas by ZIP-code–based risk.
- Uses local community planning committees
- Mobilizes existing resources (HIV, substance abuse, MCH) rather than create new.
- Trains prenatal care providers and outreach staff members.
- Hopes to eventually expand training beyond target areas.
- Plans to offer technical assistance to hospitals with high seroprevalence and low testing rates.

NY Task Force Evaluation Workgroup

Represents a wide range of agencies
Monitors program implementation.
Reviews process and outcome data.
Recommends program improvements.
Directs implementation team.
Develops evaluation strategies.

Further Questions/Issues

What are the important research questions?
How can information be abstracted from existing data?
How can we show that gains result from our interventions, not from other programs?
When are individual, rather than aggregate, data necessary?
How much data collection responsibility should be placed on community workers?

Process Measures

Outreach (number efforts, number contacts, location of contact)
Intake data (number, source, demographics and risk, pregnancy status, prenatal care status, HIV status, services received)
Referrals data (number, type, compliance)
Training (outreach workers and hospitals)

Outcome Measures

- Prenatal care use
- HIV testing patterns and rates
- Receipt of full 076 antiretroviral regimen
- Treatment rates
- Birth outcomes (e.g., birthweights)
- Knowledge, attitude, and behavior changes resulting from training (outreach workers and hospitals)

	HIV Antibody Status	Prenatal Care Counseling and Testing	Antiretroviral Use	HIV Infection Status
HIV Test History		X		
Newborn Screen	X			X
Charts (prenatal, labor, delivery, infant)		X	X	X
PCR Results				X

Resources Available to Other States

- Variables added to charts re: HIV
- Provider form
- Newborn screening form

Florida — Marlene LaLota

Evaluation of Perinatal HIV Prevention Programs

- The program began in 1994 after Pediatric AIDS Clinical Trials Group (PACTG) 076.
- It is multipronged (consumer and provider) with a wide variety of agencies.
- It is overseen and directed by an interdisciplinary workgroup.
- It is supplemented by a 1996 Florida law, which required mandatory counseling and voluntary testing.

Twofold Strategy: Educate 1) providers and 2) consumers

1. Provider Resources
   - Packet
   - Video
   - Medicaid contract
   - QI Review
   - Seminars
   - Newsletters
   - Ongoing provider training and education

2. Consumer Approach
   - Social marketing
   - *Woman's Time* newsletter

Targeted Outreach to Pregnant Women Act (provides outreach to pregnant women without prenatal care)

Evaluation Resources

- Perinatal provider survey
- PRAMS
- Pediatric HIV/AIDS surveillance data
- AIDS education training center contract
- University of Florida contract
- Hospital record and policy review (11 counties)

Evaluation Plan

- Develop assessment models to evaluate social marketing (Miami-Dade County).
- Characterize secondary data sources.
- Develop data link.

Because this is a new program, they are working to analyze and integrate data to develop an epi profile.

New/Proposed Strategies

- Electronic birth certificate for testing data
- Add variables to counseling and testing (still using old seroprevalence data)
- SCBW from 1995 (CDC)
- Children's AIDS network database (9 pediatric centers, >95% HIV-infected children, and information on maternal-infant pairs)

Workshop F: Summary

Further strategies to be developed

- Share information.
- Develop timelines.
- Distribute summaries.

Group Discussion/Questions

- How does the perinatal prevention program fit into the overall state evaluation plan?
- How can we assess the impact of perinatal programs in low infection/seroprevalence states?
- How can we integrate prevention, surveillance, and other new partners?

Workshop G: Linkages for Perinatal Prevention —Mary Willingham Wettrich, chair

Goal: To learn about and discuss the importance of linking perinatal HIV prevention activities with other relevant services. To be informed about specific models of linking services and brainstorm about potential other models

Objectives

- Become familiar with CDC and Health Resources and Services Administration (HRSA) expectations around linkages
- Learn about specific models of linking perinatal prevention activities with maternal and child health programs, private providers, women and infant programs, and family planning programs
- Discuss models of linking with additional programs serving women

Linking HIV and Maternal and Child Health (MCH) Programs —Deborah Allen, Massachusetts Department of Health

Goals of Linkage

- Integration of HIV care into "fabric" of reproductive care
- Fewer infected babies
- Earlier care for women

Linkage is Optimal Strategy

- Women are most likely to go for reproductive care.
- Women are most likely to accept testing if offered in context of care.
- Pregnancy provides a unique opportunity.

Barriers to Linkage

- Diverse systems [prenatal care, family planning, Women, Infants, and Children (WIC)], home visiting, early childhood, substance abuse, prison health)
- Complex structure within each system
- Private providers seeing themselves outside the system
- Limited time for provider and patient contact due to the multiple demands on provider

Linkage Strategy

- Analyze the problem.
- Look at the entire cascade (preconception to pediatric care).
- Pinpoint system failure.
- Identify and learn the structure of relevant systems.
- Identify or create opportunities for change.
- Make the case.
- Make it easy.

- Use pull as well as push.
- Provide feedback.

Example: Power of Persuasion
WIC º Breast-feeding º HIV
WIC has a strong message about breast-feeding. Because breast-feeding can lead to transmission of HIV, it was important to modify this message. Successful communication made this possible, and WIC changed its message to "Breast is best . . .unless you have HIV." The new message makes it important for the WIC program to encourage women to know their HIV status. As a result, a proactive approach, which addresses HIV early when a pregnant woman enrolls in WIC, permits them to be more forceful in promoting breast-feeding if they don't have to worry that some women have unidentified HIV.

MCH/HIV Integrated Project —Deanne Taylor, Cook County Hospital

This project was a HRSA 5-Year Funded Project.

Purpose: To create a perinatal HIV risk-reduction system
- For early identification
- To develop guidelines

Partnerships (between state agencies, cities, counties) were created, and an Advisory Council was developed.

Strategy was to do a needs assessment
- Survey of providers showed weak counseling and testing practices.
- Found the need to train MCH providers to integrate counseling and testing.
- Created committees to develop guidelines and policies.
- Involved consumers.
- Developed and administered a survey to determine outcomes.

Outcomes
- Trained over 4,000 providers.
- Developed written guidelines.
- Developed a patient/provider agreement. Consumers were part of this partnership, and the providers saw the consumers' involvement as being positive.

Lessons Learned
- Work within the existing system.
- Providers need user-friendly materials.
- Training is not enough.
- Written policies facilitate compliance.
- Continue to monitor the system and address barriers.

Targeted Outreach for Pregnant Women Act (TOPWA) —Frances Walker

Florida is a state with high numbers of women with HIV. Women of color are disproportionately represented. Preventing perinatally transmitted HIV requires that women have access to adequate prenatal care. TOPWA resulted from and is about collaboration with representatives from county health departments and other agencies.

TOPWA

- Is an outreach program—many outreach workers are peers.
- Resulted from state legislation.
- Is a state-run program (part of the department of health) working with community-based organizations (CBOs) in five counties with high incidence of HIV/AIDS. CDC funding will allow TOPWA to expand to an additional six counties.

Goals: By proving funding to CBOs, through county health departments, reduce the number of women who give birth to HIV-infected and/or substance-exposed newborns

Focus: Outreach

- Go out and find high-risk women, develop relationships, work nontraditional hours, start where clients are.
- Screen women for eligibility.
- Make referrals (linkages) and see that they occur.
- Develop linkages between TOPWA and service providers.
- Give community presentations.
- Negotiate special status with other agencies for high-risk clients.
- Service providers appoint a key agency contact to work with TOPWA.

Referral Process

- TOPWA agency contacts provider, clinic.
- Enrolled clients are notified of scheduled appointment and get the client there.
- Clients are called or visited to ensure appointments are kept.
- Clients who skip appointments—problems are addressed; e.g., lack of transportation or no health insurance/Medicaid.

Benefits of Collaboration

- Linkages are strengthened over time.
- Referrals are reciprocal—other agencies refer clients to TOPWA to help make connections with women to be adherent.

Hard-to-reach Women

- Work with women who are being released from jail or are “no-shows” at county health department clinics.
- Clients that are at high risk are hard to find and “disappear” if not tracked.
- Incentives (e.g., baby showers) are effective.

Workshop H: Issues of Special Populations —Janet Cleveland, chair

Goal: To familiarize grantees with the issues related to special populations such as substance abusers, women in correctional facilities, and immigrants

Objectives

- Discuss issues related to substance abusers and their special needs
- Learn more about the special needs of women in correctional facilities
- Discuss the unique needs of immigrant populations
- Learn about similar state programs to control perinatal transmission of hepatitis B

Rhode Island Department of Corrections —Jennifer Clarke

As a general statement, the majority of incarcerated women do not remain in prison for long, are involved with drug use, and are #35 years old; 25% have dependent children who live with a family member.

Key Services

HIV testing

- Optional on the day of commitment (95% accept)
- Mandatory on sentencing

HIV care

- Provided by the "A-team," an immunology center outside the jail.
- The same doctor follows up with men and women in and out of jail.
- Comprehensive care, including birth control, is provided.

Project Bridge

- Purpose: To decrease the rate of HIV transmission among high-risk women leaving prison
- Collaborative project
- Initiated at prison, continues at a community site
- Enrollment: All women at risk (history of drug use or sex trade work) are enrolled.
- Education: The women are educated about
  - Prevention of sexually transmitted diseases (STD)
  - Lower risk drug use (e.g., needle exchange)
  - Family planning
  - Drug treatment facilities
- Other efforts: Vaginitis and STD are aggressively treated.
- Results
  - Recidivism rates decrease.
  - Women are more educated about hepatitis C.

- Incarceration is an opportunity for public health interventions.

Perinatal Hepatitis B Prevention —Tasneem Malik, Centers for Disease Control and Prevention

- Hepatitis B is a public health problem.
- Hepatitis B is more infectious than HIV.
- Modes of transmission are similar to those of HIV.
- Interventions (infant) should be initiated at birth and followed up at 12 months.
- Key elements of perinatal prevention (similar to those of HIV)
  - Screening
  - Identification and reporting
  - Case management
  - Immunoprophylaxis at birth
- Reasons pregnant women are not screened (similar to HIV)
  - No prenatal care
  - No hospital written policy
- Reasons infants are not screened (similar to HIV): Infected women are not identified.
- Strategies/implementation
  - Screen all pregnant women.
  - Enhance case management.
  - Use tracking methods.
  - Use multiple reporting systems.
  - Be persistent and dedicated.
- Use other strategies: home visits, phone calls, link with other programs and offices, [Women, Infants, and Children (WIC), refugee offices], churches (send staff member who can speak the language).

Linkages Among Programs (e.g., STD, perinatal hepatitis B)

- Look for populations with similar risk behaviors.
- Look for similar reporting mechanisms.
- Look for similar monitoring activities (e.g., screening audits for both hepatitis B and HIV).
- More integration is needed among all programs.
- Use of funding from different sources will help.

Other Strategies

- Follow-up through home visits or phone calls or linkage with other programs.
- Churches are good locations for reaching immigrants.